University of Alberta

The Cancer Experiences of Chinese Immigrants to Canada

by

Agnes Cheng ©

A thesis submitted to the Faculty of Graduate Studies and Research
in partial fulfillment of the requirements
for the degree of Master of Nursing

Faculty of Nursing

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ACheng

67 Henry Avenue
Edmonton, Alberta
Canada
T5A 2X6

99-01-29

University of Alberta

Faculty of Graduate Studies and Research

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled THE CANCER EXPERIENCES OF CHINESE IMMIGRANTS TO CANADA submitted by Agnes Cheng in partial fulfillment of the requirements for the degree of MASTER OF NURSING.

Linda Ogilvie

Dr. Linda Ogilvie

P.M. Koop

Dr. Priscilla M. Koop

Kärin Olson

Dr. Kärin Olson

Lili Liu

Dr. Lili Liu

99-01-26

Ingrid Johnston

Dr. Ingrid Johnston

Dedication

This thesis is dedicated to all the participants who so graciously shared their experience with me.

Abstract

Interviews were conducted with ten Chinese-Canadian cancer patients to examine the Chinese cancer patients' information needs and decision-making preferences in regard to cancer treatment selections.

The study findings revealed that the majority of participants preferred to have their physicians select cancer treatments for them. Two participants, however, wanted the opportunity to make choices themselves. All participants wanted their diagnosis revealed and the treatment options explained. Trust in the doctors, perceived lack of relevant knowledge are reasons given for delegating the decision-making responsibility to the doctor.

In addition to the initial objectives of the research, participants described the impact of cancer on themselves and their families and shared the strategies used to cope with the cancer experience. The use of Traditional Chinese Medicine (TCM) was mentioned by some participants but others expressed concerns about the efficacy of such practices and the safety in the Canadian setting where traditional practitioners are not regulated.

Problems with language barriers, lack of awareness of existing services were some of the special issues raised by the participants. These hardships, however, were not shared by everyone.

What was most interesting about the findings was the limited way in which cultural values, beliefs and practices commonly found in the transcultural literature seemed to influence the decision-making preferences, information needs, and cancer experiences of these Chinese Canadian immigrants.

Acknowledgement

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To understand the “cultural” needs
Sameness and differences of people
Needs an open being
See-Hear-Feel
With no judgement or interpretation
Reach out
May be with that physical touch
Or eyes, or aura
You exhibit your openness and willingness to
Listen and learn
And, you tell and share
In doing so-you share humanness
It is acknowledged and shared
Something happens-
Mutual understanding

--By Rachel E. Spector (1985, Preface)--
With permission

Chapter 1

DEFINING THE CONTEXT

Canada is a pluralistic society enriched by the contributions of immigrants from all parts of the world. Of particular interest to me, both as a nurse struggling to provide culturally responsive care to diverse patient populations and as an immigrant from Hong Kong with ongoing ties to China, is how cultural beliefs, practices and knowledge affect patient care and outcomes. Do Chinese immigrants receive the same quality care experienced by other Canadians? Do we even know what such health care entails when delivered across linguistic and cultural differences?

Problem Definition

Given my Chinese heritage, immigration to Canada as an adult, and over twenty years of nursing experience in acute care and home care settings, I became interested in the experiences of adult cancer patients of Chinese origin who are first generation immigrants to Canada. More specifically, I was concerned that information needs were not being met and that decision-making preferences were neither known nor solicited. A qualitative research approach was designed to explore these concerns.

Background

With the changes in immigration law since the 1960's, Canada has become an increasingly multicultural society. Policies that restricted certain ethnic groups from entering Canada have changed. Current policy for admission is mainly based on labour market considerations and economic development needs. Under the point system, the selection of immigrants is based on the match of their training and skills with the needs of Canadian society. Immigrants selected in this way are classified as independent admissions. There is provision under immigration law for two other categories, family admission and refugee admission (Community Trends Working Group, 1991). These changes in immigration policies have resulted in immigrants to

Canada with varied socio-economic status, education and language skills.

The countries of origin of Canadian immigrants shifted with the changes in immigration policy from predominately European countries to primarily Asian countries. In Canada, the top ten places of birth for immigrants arriving (between 1991 and 1996) are Hong Kong, the People's Republic of China, India, the Philippines, Sri Lanka, Poland, Taiwan, Vietnam, the United States and the United Kingdom (Statistics Canada, 1996) with the number of Asian immigrants increasing to comprise almost half of the total (Frideres, 1992; Simmons, 1995). In recent years, Alberta received more immigrants from Hong Kong than from any other country, with China sixth in terms of country of origin of new immigrants (Alberta Development and Employment, Immigration and Settlement, 1990). Over half of the immigrants to Edmonton in 1990 had no working knowledge of English or French (Edmonton Community and Family Services, 1996).This increased diversity of people in Canadian society has serious implications for health care delivery. Our understanding of different ethnic groups is critical for delivery of high quality and culturally sensitive health care.

Brief Overview of the Relevant Literature

Much literature exists in which the beliefs, values and experiences of Chinese immigrants are discussed. Studies of Chinese Canadian immigrants describe adaptation issues such as language barriers, difficulties in accessing health services, barriers to further education and career pursuit, and health status (Anderson, Wiggins, Rajwani, Holbrook, Blue & Ng, 1995; Chan-Marples, 1993; Cheng-Jardine, 1988; Liu, 1986; McKinnon, Gien & Durst, 1996; Wittebrood & Robertson, 1991). Research on Chinese immigrants and cancer focus mostly on epidemiologic information (Hanley, Choi & Holowaty, 1995; King & Locke, 1987; King, Li, Frances, Locke, Pollack & Tu, 1985; Rosenblatt, Weiss, & Schwartz, 1996; Rossing, Schwartz & Weiss, 1995; Stanford, Herrinton, Schwartz & Weiss, 1995; Wang, Ramcharan, & Love, 1989; Wu, Ziegler, Pike, Nomura, West, Kolonel, Horn-Ross, Rosenthal, & Hoover, 1996). The few studies on Chinese cancer patients that examine the impact of cancer, coping with cancer, perceptions of cancer, and information disclosure about cancer have been done in China, Hong Kong or Taiwan (Dodd, Chen, Lindsey & Piper, 1985; Fielding, Ko & Wong, 1994; Li & Chou, 1997; Lindsey, Dodd & Chen, 1985; Ma, 1996). This information may not be transferrable to the Chinese Canadian immigrant population because of differences in sociopolitical, economic and health care environments. Research on Chinese immigrants' information needs and treatment decision-making preferences when confronted with a diagnosis of cancer was not found.

There are a number of studies done on patients' information needs and decision-making preferences with regard to cancer treatment. While some researchers found that cancer patients desire to have their physicians choose their treatment options (Beisecker & Beisecker, 1990; Degner & Sloan, 1992; Beaver, Lukar, Owens, Leinster & Degner, 1996), others found that patients desire a more active role (Blandchard, Lebrecque, Ruckdeschel & Blandchard, 1988; Hack, Degner & Dyck, 1994). In addition, the importance of information in influencing patients' decisions regarding treatments has been studied (Herr, Kornblith & Ofman, 1993; Lliewellyn-Thomas, McGreal, Thiel, Fine & Erlichman, 1991). Such studies often exclude Chinese and other immigrants, particularly when there are language barriers. While these studies review important findings on cancer patients' decision-making preferences and information needs, the Chinese cancer patients' experiences are not captured. From the literature, language difficulties among Chinese immigrants have been identified. It is also known that language proficiency is fundamental in information exchange between health professionals and patients. Given what we know thus far, it is reasonable to question how much understanding Chinese immigrants have of their diagnosis and treatment when they encounter a diagnosis of cancer in the context of an English-speaking environment.

It is common knowledge that a person's health beliefs and practices impact on perceptions of illness and treatment. Most literature outlining health beliefs and practices of Chinese people is anecdotal and incorporates a description of the practice of Traditional Chinese Medicine (Chae, 1987; Louie, 1985; O'Hara & Zhan, 1994;

Shih, 1996; Tong & Spicer, 1994). Other literature describes Chinese philosophy as conforming to nature (Chen, 1996), centering on family involvement in decision making (Muller & Desmond, 1992), dominated by respect for the social order and authority figures (Kleinman, 1980), and influenced by Confucian, Taoist and Buddhist values in relation to perceptions of health, illness and personhood (Shih, 1996). Even though this kind of information offers insights into Chinese people's values and thinking, it may underestimate the diversity within the Chinese population. It may also fail to take into account the socio-political changes that have occurred in Asian countries, and lead to inaccurate assumptions and stereotyping. Chinese immigrants come from diverse backgrounds (Hessler, Nolan, Ogbru, & New, 1978; Li, 1988). How does this diversity influence their beliefs, values and practices and, therefore, impact their experiences of cancer after immigration to Canada? Does this literature accurately describe Chinese people's current health beliefs and practices?

In the late twentieth century, there is a great deal of interest relating to multiculturalism in North-America and Europe (Satzewich, 1992). There is a growing body of knowledge in nursing that focuses on different cultural groups, including guidelines on assessing patients from different cultural backgrounds. Andrews and Boyle (1995), in their analysis of the progress of transcultural nursing, said it began in the 1960's under the influence of Leininger, MacGregor, Osborne and Clark. Development of a body of knowledge became evident by the 1970's and 1980's, while in the 1990's the field of transcultural nursing seems firmly established. There is increased emphasis on the education of nurses regarding knowledge and attitudes needed to deliver culturally sensitive care in order to promote the health and well-being of people from different cultures. To this end, theories of cross cultural care have been included in many nursing curricula in recent years.

Nurses have it in our mandate to deliver culturally sensitive care, and to advocate the importance of research-based practice. Reflecting on the literature, it is obvious that not a lot is known about Chinese immigrants who suffer cancer. More specifically, not much is known about their treatment decision-making preferences or their information needs. It is important to determine what issues they are confronting, including differences and/or similarities to other Canadians' experiences, as presented in the research literature. Do Chinese immigrants who experience cancer have needs that are not being met?

Research Questions

Based on my concern and review of existing literature, the following questions were developed.

1. What information needs do Chinese-Canadian patients perceive in relation to their diagnosis, treatment and prognosis?
2. What understanding do these patients have of the verbal and /or written information given to them regarding treatment options?
3. What decision-making role do Chinese-Canadian patients prefer?

Reconceptualization of the Research Questions

As data collection progressed, it became evident that the population in this study was not homogenous. Participants belonged to different social classes and had variable beliefs, values, and health care experiences. My preconceived assumptions regarding their decision-making preferences and approach to the cancer experience were challenged by what participants were saying. This led to the in-depth review of literature relating to Traditional Chinese Medicine, health care in the countries of origin of many Chinese immigrants to Canada, and health practices, health care beliefs and values of Chinese persons that is presented in Chapter Two. Why was what I was hearing from the participants different from what I as a Chinese-Canadian nurse expected to learn?

As data collection continued, the participants' willingness to speak of the impact of cancer on their lives and how they managed to cope with the situation became important findings, even though it was not part of the research as initially conceptualized. Therefore, the construction of this thesis shifted to include not only a description of the Chinese cancer patients' treatment decision-making preferences and information needs, but also their observations on the impact of cancer diagnosis and treatment on their lives, including coping strategies used.

In reporting the research findings, this thesis is divided into seven chapters. Thus this first chapter serves as an introduction and a brief discussion of the questions raised as the research process unfolded. Chapter Two is the literature review of Chinese immigrant issues and Chinese health beliefs and practices. It includes a brief overview of Traditional Chinese Medicine (TCM) and health care systems in the countries of origin of Chinese immigrants to Canada. Chapter Three is the literature review on cancer treatment decision-making and the issues that surround it. Chapter Four describes the research process. The research findings are outlined in Chapters Five and Six. Synthesis and discussion of findings are found in Chapter Seven.

Chapter Two

CHINESE IMMIGRANTS TO CANADA: THE CULTURAL CONTEXT OF DECISION-MAKING PREFERENCE

Kleinman (1988) defined the illness experience as "how the sick person and the members of the family respond to symptoms and disability" (p.3). The illness experience is how the sick person and his/her family categorize and explain the disease. It includes the distress caused by the disease, a judgement on how best to cope with this stress, and the impact on day to day living. The illness experience is always culturally shaped.

Participants in this study include immigrants who came to Canada from China, Taiwan and Hong Kong. In order to understand these immigrants' illness experiences, it is important to examine the contexts from which they came and their experiences in encounters with health care in the host society. For this reason, the review of the literature includes a discussion of the major concepts of Traditional Chinese Medicine (TCM), a description of the medical systems in China, Hong Kong and Taiwan, and a brief overview of the beliefs and health care experiences of Chinese immigrants to North America. While brief, this overview of cultural concepts and related literature will assist in conceptualizing this research.

Traditional Chinese Medicine

The History of Traditional Chinese Medicine (TCM)

Chinese medicine has a long history. Ergil (1996) states that the origin of Chinese medicine is mythically linked to three legendary emperors; Fu Xi (the Ox Tamer), Huang Di (the Yellow Emperor), and Shen Nong (the Divine Husbandman or the Fire Emperor). They existed in what is described as the legendary or ancient period of China, from 2697-1122 B.C.E. (Wong and Wu, 1973). The famous Chinese classics (the Book of Changes, the Divine Husbandman's classic of the Meteria Medica, and the Yellow Emperor's Inner Classic) are thought to have originated at this time. There is no agreement on the authenticity of these books or the dates that they were compiled. It is likely that additions and revisions were made by several authors, with the current form dating from the Han Dynasty around 206 B.C.E. to 25 C.E. (Hoizey & Hoizey, 1993).

Wong and Wu (1973), in their discussion of the history of Chinese medicine, said that more reliable history began in the middle of the Chou Dynasty (722 B.C.E.), which is considered the most glorious period in Chinese history. This dynasty is often represented as the age of philosophy because the most famous philosophers (Lao Wzu, Confucius and Mencius) lived during this period. The study of medicine was dominated and influenced by philosophers and scholars at the time. Around 400 B.C.E., there emerged an understanding that all phenomena existed in dualistic and complementary forms (Unschuld, 1985). As a result of these varied speculations there evolved two doctrines which form the basis of TCM. The first is the doctrine of the Two Principles called Yin and Yang and the second is the doctrine of the Five Elements. In medicine, everything is classified under the divisions of Yin and Yang. The universe with its dual forces is considered a macrocosm while man is a microcosm or "little universe". Chinese medicine reached its zenith during the Han (221 B.C.E. to 220 C.E.) and T'ang (581-907 C.E.) dynasties, when the influence of TCM was extended over a wide geographic area. Its fame extended south to Annam and Siam and north to Korea and Japan (Wong & Wu, 1973).

The Philosophy of TCM

The philosophy of TCM begins with the principles of Yin and Yang (Ergil, 1996). Yin and Yang express the idea of opposing but complementary phenomena that exist in a state of dynamic equilibrium. Yin is characterized as dark, earth, moon, night, autumn, winter, cold, female, slow, down, inside, water and metal. Yang is conceptualized as light, heaven, sun, day, spring, summer, hot, male, fast, up, outside, fire and wood. Another principle that has played a significant part in the development of Chinese medicine is the notion of the Five Elements (wu xing), which are described as earth, metal, water, wood and fire. All phenomena in the universe are organized with respect to the Five Elements, from seasons of the year to body organs. These Five Elements interact in a nourishing and controlling fashion with one another, and the ultimate result is to achieve balance. For example, the liver and gall bladder are classified as wood, the small intestine and heart are classified as fire, and the kidney and bladder are classified as water. Wood nourishes fire, and water controls fire. Therefore, the kidney and bladder control the energy within the heart and small intestine. Both Yin and Yang and the principles of the Five Elements are the basis for diagnosis and treatment of illnesses.

The concept of Qi (also known as Chi) is the idea that the body is pervaded by subtle material and mobile influences (energy forces) that cause most physiological functions and maintain the health and vitality of the individual (Ergil, 1996). Illnesses are attributed to the disturbance of the Qi within the body. The location of disturbances is expressed and can be observed as signs and symptoms. Monte (1993) described Qi as the life force that results from the attraction between Yin and Yang within the body. According to Gigante and Zhang (1996), Chinese thought regards Qi as the fundamental substance constituting the universe. All phenomena are produced by change and the movement of Qi.

Ergil (1996) described the five types of Qi as ying, wei, jing, zang, and zong Qi. The ying Qi supports and nourishes the body. The wei Qi protects and warms the body. The jing Qi flows in the channels which can be felt during acupuncture. The zang Qi flows in the organs. The zong Qi is responsible for respiration and circulation. Together with Qi, Essence and Spirit make up what are known in Chinese Medicine as the "Three Treasures". In brief, Essence is the gift of one's parents and Spirit is the gift of heaven. Ergil (1996) said that Essence is the most fundamental source of human physiologic processes. Essence includes the bodily reserves that support human life and that must be replenished by food and rest, and includes the reproductive substances of the body. Spirit is the alert and radiant aspect of human life. We encounter it in the luster of the eyes and face in healthy persons, as well as in their ability to think and respond appropriately to the world around them. The idea expressed by Spirit or Shen in TCM encompasses consciousness and healthy mental and physical functioning.

In TCM, diseases are ascribed to one of three possible causes. They may be classified as external, internal or nonexternal/noninternal (Ergil, 1996). The external causes, also known as the “six evils”, are wind, cold, fire, damp, summer heat, and dryness. The internal causes are the result of internal damage done by the seven affects of joy, anger, anxiety, thought, sorrow, fear, and fright. The nonexternal/noninternal causes are dietary irregularities, excessive sexual activity, fatigue, trauma, and parasites. The methods of diagnosis are inspection, listening, smelling, inquiry and palpation (which includes pulse examination). The primary therapeutic concept is to address the pathologic condition with opposing measures. Therefore, cold is treated with heat, heat is treated with cold, vacuity is treated by supplementation, and repletion is treated by drainage. The therapeutic methods are acupuncture, moxibustion, cupping, bleeding, Chinese massage, Qi cultivation, Chinese herbal medicine, and dietetics.

The Practice of TCM

The therapeutic use of food is a major tenet of TCM and thus is given as an example of how TCM is applied in practice. In his discussion of Chinese dietetics, Lu (1986) suggests the book called One Thousand Ounces of Gold Classic as a reference. In this classic, the dietary treatments of various diseases are discussed. Basically, a balanced diet means two different things. First, it means that you should eat foods of various flavours, energies, and organic actions. For example, beef is considered neutral in energy, sweet in flavour, and acts on the spleen and stomach. Second, a balanced diet also means that foods are selected according to a person’s needs and physical constitution. The first is called the common balanced diet and the second is called the individual balanced diet. The sense of a balanced diet is quite different from the meaning of a balanced diet in the Western sense. The foods that one enjoys and eats most frequently tend to be sweet foods, followed by salty foods; therefore, to achieve a balanced diet, a person needs to eat more pungent, sour and bitter foods to restore the flavour balance. The organic balance pertains to the organic condition.

Each individual has organic strengths and weaknesses. When one organ is excessively strong it could weaken other organs, creating organic imbalance. For example, eating cold foods to treat a "hot stomach" would restore the normalcy of the stomach and rebalance the bodily organic function. To achieve a balanced diet, each person's physical constitution must be considered. There are six different types of physical constitutions: hot, cold, dry, damp, deficient, and excessive. For example, a person with a hot physical constitution should eat more cold and cool foods. The energies and flavours of foods are also classified into Yin and Yang. Hot and warm energies are Yang; cool and cold energies are Yin. Pungent and sweet flavours are Yang; sour, bitter and salty flavours are Yin. When the foods are classified into Yin and Yang, both their flavours and energies are considered. Sometimes, the energy of a food may be Yang and its flavour Yin.

Research from the 1970's and 1980's confirms the importance of traditional dietary beliefs for contemporary Chinese families in Hong Kong, the rural New Territories and Taiwan. Precise knowledge of how the system works, however, was unusual in the general population. Koo (1984), in her study of Chinese families in Hong Kong, found that her participants believed that following certain food prescriptions and proscriptions would provide additional benefits for recuperation, regardless of the ailments. She concluded that the Chinese method of dietary manipulation has been adapted to play a complementary role with Western medicine in the multiple stages of the disease process. Adherence to dietary rules was pervasive among the lay public in Hong Kong, as was reliance on Chinese herbalists and other traditional practitioners. This occurred in spite of the fact that Western medicine is offered at minimal cost by the Hong Kong government, and is the only medical system sanctioned by the government and educational authorities. People had to pay additional money to access TCM.

In their study of communities in rural New Territories and Malaysia, Anderson and Anderson (1975) found that Chinese people believe that "hot" foods, notably protein foods like meat broth, are thought to strengthen the "Chi" (Qi) and foods that are "cold" would weaken it. Most people, however, failed to agree with each other on what foods are hot or cold and were vague about the list of hot or cold foods. Gould Martin (1975) found that the Taiwanese Chinese believe in the concept of "patching", which is synonymous with strengthening, and that patching can be achieved with foods or herbs. Thus, in the countries of origin of many Chinese immigrants to Canada, TCM is a factor in health seeking behaviours, although many immigrants may lack a sound knowledge of TCM and may not be clear about how to apply it for their own benefit.

Traditional Chinese Medicine, therefore, is a complex system that has evolved over centuries. While still practised in Taiwan, Hong Kong and China, it coexists with biomedicine, called Western Medicine throughout this thesis. There are also inconsistencies in how the lay public integrates TCM into the illness experience in these common countries of origin of Chinese immigrants to Canada. There is, in addition, evidence that shamanistic beliefs and practices existed historically and could have some influences in the present (Unschuld, 1987).

Health Care Pluralism in Hong Kong, China and Taiwan

Western Medicine was introduced into China by Catholic missionaries between 1600 and 1800 C.E. From 1820 to 1842, the first Dutch and British surgeons were stationed in China. Dispensaries for the Chinese opened in 1820 C.E. and a missionary hospital was opened in 1835 C.E. in Macao. Western medicine continued to flourish in China. Similar activity was happening in Hong Kong. In 1887, the medical college for Chinese students was formed. It was attached to the Alice Memorial Hospital in Hong Kong and had the first graduates in 1892 (Wong & Wu, 1973). Thus Western Medicine has been practised in China and Hong Kong for over a century. A similar pattern is seen in Taiwan (Chi, 1994).

China

While TCM developed and accumulated for more than three thousand years, dominating the health seeking behaviours of Chinese people for generations, and is considered the "great tradition in China", the introduction of Western Medicine challenged this tradition. By the first half of the twentieth century, the realm of medical and health services in China was dominated by Western Medicine (Wong & Wu, 1973). When the communist government took over mainland China, a revivalist movement emerged. Efforts were made to re-examine Chinese Medicine's techniques and theoretical rationales, to upgrade its quality, to widen its use, and to integrate it with Modern Western Medicine. Cai (1988), in his discussion about China's pluralistic medical system, suggests that modern (Western) medicine uses the modalities of chemotherapy and radiation to treat cancer effectively, but that treatment reactions can be greatly lessened by the use of Traditional Chinese Medicine and therefore the treatment outcome is enhanced. Forgac (1994) observed in China that both medical systems are used to treat cancer. She said that diagnosis of cancer is done using CT scan technology, combined with the TCM doctor's pulse reading, tongue and facial pallor examination, and questioning. While Western Medicine uses surgery, radiation and chemotherapy, which cause side effects and weaken the person, the TCM practitioner uses herbs to increase strength and bolster the patient's immune system. These herbs may stimulate appetite and increase recovery rates for cancer. The two medical systems in China coexist and complement one another. Practitioners of both TCM and Western Medicine may be employed within the same health care setting.

Hong Kong

Hong Kong, once it became a British Colony in the late nineteenth century, industrialized rapidly. Traditional Chinese Medicine and Western Medicine coexisted but were not equally valued. The Hong Kong Government and the Medical Council of Hong Kong played vital roles in endorsing the Western medical model. Only the Western medical doctor, who held a diploma granted by the Hong Kong University or a program recognized by the General Medical Council of the United Kingdom, received legitimation. Traditional Chinese Medical practitioners were excluded from the council and their services were not recognized by the legal authorities. They were denied certain privileges such as issuing death certificates or undertaking surgical operations (Lee, 1975).

Traditional Chinese Medicine, however, continued to exist in Hong Kong. The local population continued to trust and depend on TCM, using the rationale that because it has existed for so many years it must be valid. A survey of 702 Hong Kong Chinese (Lee, 1975) revealed that 84% of informants believed that Western medicine is more effective in the treatment of most diseases. An even greater percentage, however, believed that Traditional Chinese Medicine is better in promotion and maintenance of health. While Western Medicine is more widely used, nearly 50% of Chinese people use both types of medical care. By tracing people's health seeking patterns, Lee found that people frequently began with self-medication. When such efforts failed to relieve symptoms, then help from either a Western medical doctor or a TCM doctor was sought. Patients would shift between the two medical systems until satisfied with the outcome. This pattern of health care utilization was confirmed by Cheung, Lau and Wong (1984) when he examined health seeking behaviours of mental health patients. As Western Medicine is funded by the government and patients pay minimal fees while TCM is not funded and thus more expensive, this kind of utilization reflects the value attributed to TCM.

Taiwan

Both Traditional Chinese Medicine and Western Medicine coexist in Taiwan (Chi, 1994). From 1895 to 1945, Taiwan was under Japanese rule as a result of the Shimonoseki Treaty. The Japanese government endorsed Western Medicine and TCM was severely suppressed during that time. In 1945, when the Nationalist government took over Taiwan, a change in policy allowed both medical systems to coexist, resulting in increased numbers of traditional Chinese medical practitioners. Even though more emphasis seems to be placed on Western Medicine, reflected in more resources allocated to Western Medicine, TCM is in great demand by the people. Current health insurance in Taiwan covers TCM as well as Western Medicine.

In rural Taiwan, three types of medicine are practised; Chinese Sacred Medicine (shamanism), Chinese Secular Medicine (TCM), and Western Medicine

(Gould Martin, 1975). When the Taiwan Chinese people were asked to compare Chinese and Western Medicine, the comments were: Chinese Medicine is slow and Western Medicine is fast; Western Medicine hurts the stomach and Chinese Medicine is gentle; each has advantages and disadvantages; and, Chinese Medicine is better for women's troubles and broken bones and Western Medicine is better for acute disease. The most common response when comparing Western Medicine and Chinese Medicine was that the former cures the symptoms and the latter cures the cause.

Medical Pluralism in Hong Kong, China and Taiwan

Chinese people who immigrate to Canada are familiar with multiple medical systems. Medical pluralism is evident in Hong Kong, China and Taiwan. Forgac (1994) said medical pluralism occurs when several medical systems work together within a community. The People's Republic of China has a model of medical pluralism because biomedicine, TCM and minority medical traditions such as Tibetan or Mongolian medicine and shamanistic practices function in the same arena. Yeung (cited in Forgac, 1994) states that there is benefit to coexisting multiple medical systems as people can choose a different medical approach depending on the need of the particular situation. Akerele (1984) advocates incorporating traditional medicine with biomedicine as a way to provide inexpensive health care. Simple remedies for common ailments can be made from the local pharmacopoeia, thus eliminating the need for expensive drug therapy.

The theory that supports Traditional Chinese Medicine is complex. Since Traditional Chinese Medicine is practised to varying degrees in China, Hong Kong and Taiwan, the understanding of these theories among lay persons varies as well. When Chinese people immigrate to Canada, they bring with them their previous experience with Traditional Chinese Medicine and with Western Medicine. When they become ill, their illness experience is shaped by their belief in Chinese Medicine, their previous experience with Western Medicine, their immigration experience as a newcomer, and their encounters with the health care system in Canada. The experiences of Chinese immigrants, their health beliefs, and their encounters with the health care system in Canada are discussed next.

Chinese Immigrants in Canada

The History of Chinese Immigration to Canada

There is a long history of Chinese immigration to Canada. Chinese men first came to Canada in the 1850's although Chinese women were not present until the 1950's. Chinese immigrants came to Canada for economic gain. The earliest immigrants came to Canada to provide labour in building the railroad and were met with hostility and rejection and their lives were full of hardship and loneliness (Pettigrew, 1988). Immigration policy did not permit family union until the 1950's and the early Chinese communities are described as "bachelor communities" (Cheung, 1984).

Changes to immigration policy in recent years has allowed for increased diversity of immigrants to Canada. In Alberta, prior to the 1960's the majority of immigrants to Canada were from Europe. In the 1990's, more immigrants are from Asia and non-European countries. People born in Asia and the Middle East made up just over half (55%) of the immigrants who came to Edmonton between 1981 and 1991, as compared to 4.1% before 1961. From 1985 to 1990, about four in ten persons (38.1%) who migrated to Alberta arrived under either family immigrant status or business immigrant status (i.e. entrepreneurs, self-employed persons and investors). Edmonton's share of newcomers is about 42% of the Alberta total in any given year (Edmonton Community and Family Services, 1996). This results in diverse socioeconomic status among Chinese immigrants in Edmonton. Immigrants accepted under business class status are affluent while there is great variation in the incomes of family status immigrants.

The Chinese Community in Edmonton

The demographic characteristics of Chinese immigrants in Edmonton, like Chinese immigrants in the rest of Canada, have changed. Cheung (1984) said that while 21.3% of the Chinese population in Edmonton reported English as their mother tongue and 76.5% of Chinese people claimed Chinese as their mother tongue, only 59% of the same population were born outside of Canada. The Chinese community is well-educated as 20% are university graduates compared to 11.5% in the general population. On the other hand, there is a high proportion of people (33.6%) with grade 10 or less of formal schooling. Chinese Canadians are in all types of jobs. Compared with their fellow Edmontonians, there is a higher proportion of Chinese persons in service, engineering and health; a comparable proportion in managerial administrative positions; and a lower proportion in sales, construction and trade. Cheung (1984) also described religion among the Chinese population in Edmonton and found that the bulk of the Chinese community (61.8%) has no religious preference as compared with only 12.4% in the overall population of Edmonton. Of those who have religious preferences, the largest groups are Protestant (15.2%) and Catholic (12.2%). A smaller proportion are Buddhist, Confucian and Taoist. Recent immigration patterns of Chinese immigrants to Canada could have changed this demographic profile.

The Immigrant Experience

Immigration is believed to be a stressful experience because of cultural and societal change, economic and employment concerns, isolation from family and social networks, and problems with language and discrimination (Aroian, 1990; Canadian Task Force, 1988; Chae, 1987; Kuo & Tsai, 1986; Naidoo, 1988; Lipson & Meleis, 1985; Ng, 1993; Tabora & Flaskerud, 1997; Weeks & Cuellar, 1983; Wittebrood & Robertson, 1991). Research has supported the view that immigration stress influences the onset of mental illness in some newcomers. Kuo (1984) studied mental illness among Asian Americans and concluded that migration stress and decreased employment status are factors that place this population at risk for mental illness. Liu (1986), in a study of American Chinese elderly, found that they suffered loss of support and kinship ties as a result of international migration and the earlier discriminatory immigration law. Chinese seniors faced problems such as language barriers, congested housing, concentration in the ethnic ghetto (Chinatown), lack of access to health care, and lack of ability to communicate with their physician. Kuo (1984), in a study of Chinese, Japanese, Filipino and Korean immigrants, found that many reported adaptation difficulties. Difficulty with the English language and homesickness were perceived as the greatest problems, followed by the lack of ethnic support networks and problems adjusting to American lifestyles. A lack of language proficiency leads to isolation and loneliness and results in a sense of being a "marginal" person in the society (Canadian Task Force, 1988). These Asian immigrants were at risk for depression (Franks & Faux, 1990; Lam, Pacala & Smith, 1997; Mui, 1996).

Immigration experiences are not always negative. Kuo and Tsai (1986) stated that studies on immigration may have overstated the negative effects. It is important to differentiate the conditions of migration, the characteristics of the migrant groups, and the conditions in the receiving society. For example, Aroian (1990) studied the experience of Polish immigrants. Positive aspects of immigration, such as self-growth, financial opportunities and increased freedom were described. From this research, stages of adaptation were described as: 1) loss and disruption; 2) novelty; 3) occupation; 4) language; 5) subordination; and, 6) feeling at home. He said that the psychological adaptation to migration and resettlement required the dual tasks of mastering resettlement demands while grieving and resolving the losses left in the homeland. Adaptation to the host society takes time and effort.

Adaptation to the host society is made easier by a support network (Kuo & Tsai, 1986; Lee, 1996). This support network could include close relatives and friends, involvement in an ethnic community, and/or organized support programs that emphasize ethnic identity (Wittebrood & Robertson, 1991). In a study of new immigrants who had been in Canada for less than a month and were attending an English as a Second Language (ESL) class, Ng (1993) found that training them to be volunteers, and then placing them in different agencies, increased their confidence and readiness to interact with others beyond the Chinese circle. The participants used volunteer placement as a channel for developing a sense of "social connectedness" which strengthened their abilities to create relationships across cultural differences.

Thompson (1987) discussed a community health program that linked non-English speaking immigrant women to the community and to one another and educated them regarding the health services available. It was found to be an effective way to ease their transition into Canadian society.

Values and Beliefs of Chinese Immigrants

There are few empirical studies that examine Chinese immigrants' health beliefs. Discussions typically refer to studies done outside of North America. Kleinman (1982), in a study of mental illness among the Chinese in China, found that 23% of his subjects in Hunan sought sacred folk treatment and 14% resorted to Shamans, sorcerers or other illegal religious experts. Yap (1967) found belief of a demonic cause for mental illness among the less educated Chinese in Hong Kong. Koo (1984) studied the Hong Kong Chinese and found that they believed in the use of food to maintain and restore balance in order to prevent and treat illness. She also found that the Chinese tended to integrate Western ideas with their knowledge of TCM in explaining and treating their illness, rather than accepting one system and rejecting the other. She found that the therapeutic use of foods is prevalent among the Hong Kong Chinese. When the Western nutritional ideas were used, they usually were applied in the context of giving additional rationalization for traditional remedies. Therefore, foods said to be rich in vitamins and protein were classified as tonics or considered to be of high nutritive value in a Chinese sense. As health beliefs of a population do not change overnight, these studies may lend insights to what Chinese immigrants may believe. We cannot, however, directly accept findings from Chinese immigrants' countries of origin as valid indicators of their beliefs after immigration.

Other literature on Chinese immigrants' health beliefs and values is mostly anecdotal and from American sources (Chae, 1987; Louie, 1985; Ludman & Newman, 1984; O'Hara & Zhan, 1994; Shih, 1996; Tong & Spicer, 1994). Tabora and Flaskerud (1997), in interviews and focus groups with Chinese women, found that participants believed in health as a state of equilibrium. The Chinese women believed that mental illness may be caused by an imbalance between hot and cold elements, excessive worry or activity, and excessive crying and anger. They believed that treatment for mental health problems could be dietary and that hot and cold foods have a role in treating mental disease.

The beliefs and values of Chinese immigrants which dictate how they manage interpersonal relationships and life events can be found in other anecdotal literature. The three schools of thought that influence the Chinese most are Taoism, Confucianism and Buddhism (Shih, 1996). Taoist, Confucianist and Buddhist systems of thought together lay a firm theoretical foundation for Chinese people's perceptions of health, illness and personhood. Concepts of life, purpose and the meaning of life are fundamentally different between Chinese and Western cultures. The Confucian teachings which advocate political and social order are particularly powerful in influencing Chinese behaviour and provide detailed rules and regulations for creating an maintaining order (Shih, 1996).

According to Shih's analysis (1996), Buddhist philosophy preaches the impermanence of the world, the emptiness of life, and the transience of all objects. Buddhists usually give a positive meaning to suffering and believe that accumulation of good deeds through compassion will enable them to reach higher states of being in the world of eternal life. The Confucian philosophy allows fate to guide one's life. There is also a belief in "Chung-Yung", which asks people to maintain a middle or neutral position when examining all phenomena. The Taoist philosophy advocates nonaction, detachment from the world, and allowing things to be. It is a philosophy of "let it be", guided by simplicity and spontaneity.

According to Shih (1996), a sick person is considered weak, dependent, vulnerable and needing help and protection. Chinese family members usually wish to meet the needs of the patient because they feel it is their duty to do so. Chinese people believe in the value of filial piety and the elderly are respected and given care (Yeo, 1995).

In terms of interpersonal relationships, Shih (1996) said that the Chinese give much emphasis to loyalty, which is interpreted as unquestioning allegiance to superiors that demands total subordination. In a health care relationship, it could mean a total submission to their physicians. If Chinese patients have questions, they usually dare not ask the physician directly. Louie (1985) said that Confucian teachings continue to permeate the lives of many Chinese and their families. The Chinese believe in moderation and harmony, politeness and restraint. Therefore, open confrontation, disagreement and conflict are discouraged. She further stated that nurses and physicians are considered authority figures and experts. Therefore, disagreement with prescribed interventions and treatments usually is not verbalized. Kuo and Kavanagh (1994) also found that the Chinese believe in deference to authority. In a therapeutic relationship, they may not ask questions or show outward disagreement even if they do not really agree. Kleinman (1980) made similar observations when studying the Chinese in Taiwan in the 1970's.

In one study Chinese seniors' beliefs about health and illness were sought (Chen, 1996). A philosophy of conforming with nature was described and findings were divided into three themes: harmonizing with the environment; following bliss; and, listening to heaven. Through interviews, Chen found that Chinese seniors believe in and seek a satisfying social life, happiness, and peace in order to promote health and prevent illness. It was a grounded theory study with a sample of 21 Chinese immigrants who were 60-90 years old, well educated, and Christians who had immigrated from China and Taiwan.

Anecdotal literature can be found in which family values among the Chinese are discussed. Lee (1975) observed that family influence was significant in the decision- making process regarding where to seek care and from whom to seek it. Yeo (1995) said that the Chinese are family centred and that family involvement in decision-making is strong. Lin, Inui, Kleinman and Womack (1982) said that Chinese immigrants often hold family-centred values which could distance them from the host society.

There are American studies that examine family values within the Chinese culture. Lin, Milton, Poland, Nuccio, and Yamaguchi (1991), in a study of Chinese mental health patients, found intensive and tenacious family involvement in caring for family members who have mental illness. They suggested that this characteristic is evident not only in the first generation immigrant, but seems present in the second and the third generations as well. The importance of family is also reflected in Chinese patients' health care decision-making processes. The family model of decision-making among the Chinese is supported by Muller and Desmond (1992) in their presentation of a case study in a clinical setting. While Muller and Desmond (1992) found that the Chinese family is much involved in end of life decisions, Crain's study (1996) indicates the danger of drawing conclusions prematurely. In a comparative study of 60 Chinese and 60 Caucasian seniors, the interview data revealed that 52% of the Chinese elderly chose a physician to speak for them if they were not able to as compared to 58% of the non-Chinese who chose a family member. These findings challenge some of our assumptions about family roles in Chinese immigrant families.

Encounters of Chinese Immigrants with North American Health Care Systems

There are American studies that describe Chinese immigrants' health status (King & Locke, 1980; Li, Schlief, Chang, & Gaw, 1972; Liu, 1986; Tabora & Flaskerud, 1997; Yu, 1986). In Tabora and Flaskerud's study of Chinese mental patients (1997), the subjects gave reasons for the Chinese immigrants' lack of use of the mental health services. Cost, lack of language match and/or culturally responsive services, and lack of knowledge of the available services were identified as barriers to care. Seventy-six percent of the respondents believed that language was a barrier when seeking help. Tabora found that immigrants who were younger, more educated, in the United States longer, and more affluent experienced fewer communication problems when seeking help.

In terms of health services utilization, Tabora and Flaskerud (1997) found that 62% of the women reported going to Western doctors for medical problems, 27% reported using both Western and Chinese doctors, and 8% used only Chinese doctors. A third of the subjects reported using Chinese medicine for self treatment. Liu (1986) said culture influenced health care service utilization and that Chinese immigrants in the Boston area sought both Western and Chinese medical services. Fong (1997) suggested that language deficits impede Chinese immigrants' utilization of services. Tabora and Flaskerud (1997) also found that people who were less acculturated demonstrated greater adherence to Chinese culture and traditions, such as turning to family and friends for help and keeping emotional problems to themselves. She measured acculturation using age, age at migration, length of time in the United States, years of education, and family income. Among her subjects, she found variation in adherence to and knowledge of traditional medical beliefs.

Literature from Canadian sources also supports that Chinese immigrants encounter difficulties when accessing health care services (Anderson, 1986; Anderson, 1991; Anderson, Wiggins, Rajwani, Holbrook, Blue & Ng, 1995; Chan-Marples, 1993; MacKinnon, Gien, & Durst, 1996; Wittebrood & Robertson, 1991). Examples of barriers included dissonance in expectations between practitioners and immigrant families, language barriers, and lack of awareness of the existing health care services. Anderson (1991), in her study of Chinese immigrant women in Vancouver who have diabetes, found hardships increased when coping with chronic illness. One of the difficulties was job-related. As Chinese immigrant women often occupy jobs that have limited benefits, they may feel it necessary to hide their health problems for fear of losing their jobs. They may not follow the diabetes regime of testing blood glucose levels and taking medication at work. This practice makes their diabetes management more difficult. Anderson et al. (1995) found good diabetes management was affected by factors such as ability to access resources, language, social support and professional relationships. MacKinnon, Gien, and Durst (1996), in a study of Chinese seniors, found that they expressed dissatisfaction with their lack of input in decision-making. When they were asked to make decisions, however, they felt inadequate because of the language difficulties which impeded their understanding, resulting in their unwillingness to be involved in the decision-making. This further increased their feelings of being burdens to their families.

In dealing with Chinese immigrants' difficulties, Louie (1985) cautioned nurses to be sensitive to Chinese patients' beliefs about health and illness. Leininger (1977) said nurses should be aware of how the cultural diversity of the patients we serve affects their needs for nursing care. Fong (1985) stressed the importance of cultural assessment in providing nursing care and identifying intra cultural variations. Anderson (1990) suggested health care professionals need to provide adequate interpretation services when there are language barriers, have meaningful dialogues with patients to understand their points of view, and be willing to learn from the patients. She said it is important that health care professionals understand the meaning and explanation that patients attribute to their illnesses and to their views of the treatments.

Culture Versus Acculturation as an Explanation of Differences

Louie (1985) defined culture as a dynamic process in which beliefs and behaviours change over time. Leininger (1977) defined cultural diversity as the overt and covert differences among people of different population groups with respect to their values, beliefs, language, physical characteristics and general patterns of behaviour. Acculturation can be seen as a process by which an individual of a different culture integrates into a new culture, taking on new cultural expressions.

Studies often use acculturation as a predictor or an explanation of the findings. Klatsky and Armstrong (1991), in their study of cardiovascular risk of Asian Americans in Northern California, found an increased incidence of smoking among Chinese American women and hypothesized that it was likely due to acculturation. Chinese women may have felt less pressure to refrain from smoking because there was a general acceptance of women smoking in the United States that was not found in their countries of origin. Furthermore, they also found no significant differences in cholesterol levels among American-born and foreign-born Asian Americans, and suggested acculturation in dietary practices as a possible explanation for the lack of difference. Differences had been expected as cholesterol levels in Asian populations are generally lower than in equivalent North American populations. They said that it was possible that the immigrants became quickly acculturated and ate more high fat foods, or it could be that the second generation Americans chose to maintain their native dietary practices and other factors were involved.

In the editorial comments, Yu (1991) critiqued Klatsky and Armstrong's (1991) explanation. She said that there was no clear understanding of Asian immigrants' dietary practices prior to immigration and following immigration. Therefore, it is difficult to draw conclusions on the change or the lack of change. She said that it was possible that the immigrants had integrated Western foods with their traditional diet prior to immigration. Yu (1991) cautioned against the indiscriminate use of acculturation in explaining research findings. Acculturation is dependent on external factors such as length of residence and affiliation to the practices of the new culture as well as internal factors such as attachment to old culture, age, education, gender etc.. Leong (1996) said that there are no valid and reliable measures of either acculturation or ethnic identity. Therefore, using these variables as explanations may create biases. Furthermore, acculturation is not a uniform process. Colonization, travelling and through the mass media, resulting in people's increased exposure to another culture. A certain degree of acculturation may have occurred prior to immigration.

Reflections on the Literature

Much of the literature on Chinese immigrants is anecdotal. Even though this information provides insight for this population, it may also overgeneralize the extent of adherence to what are labelled traditional beliefs and practices. More research information is available in the United States than in Canada. Even though American studies provide some information about the Chinese American population, the differences in political and health care environments must be considered when interpreting the relevance for the Chinese Canadian population. There is a great need for well-conducted studies on the Chinese population in Canada to improve our understanding of their beliefs, values and health care needs.

What we do know is that health care systems in the countries of origin of Chinese immigrants to Canada are pluralistic. Western Medicine is not new to this population and traditional health care practices, even in their countries of origin, may not always be the first or only choice made when seeking health care treatment or advice. In the next chapter, the review of literature will be extended to address issues related to cancer experiences and decision-making preferences in both the general Canadian and North American population and in the Chinese immigrant population.

Chapter Three

CANCER IN THE CHINESE IMMIGRANT COMMUNITY: WHAT DO WE KNOW?

Chinese immigrants to Canada bring their prior experience with them. This background colours their interpretation of experiences as immigrants. When they become ill, they come into contact with the Canadian health care system, a system with its own culture. Canadian immigrants' past experiences dictate how they enact the sick role and how they interact with health care professionals. In turn, the responses of health care professionals are based on their view of the clinical situation, their cultural sensitivity and their knowledge of the patient's preferences for information and decision-making regarding their illness. In the context of cancer, these interactions may be further coloured by patients' and caregivers' views of the disease. While we examine the uniqueness of the Chinese immigrants' experience with cancer, we need to look at some of the existing literature on people's cancer experience in general.

The Cancer Experience

Cancer as a Disease

Cancer is a much feared disease as recurrence rates are high for some cancers and treatment success remains elusive for many cancer sites. Kleinman (1988) states that "cancer points up our failure to explain and master much in our world" (p. 20). In depicting the cancer diagnosis, Martin (1986) said," We are tattooed and branded by cancer in a special way because this brand carries with it such dread, such loathing, such anger, such pain, such fear, as to defy description in any language, in any terms at all. What it confronts us with the most, of course, is the inescapable sign of our mortality" (p.98). Cancer is feared because it forces people to face their mortality.

Cancer Mortality and Morbidity

The prevalence of cancer varies depending on the type of cancer, geographic location, age and race. Armstrong (1980), in his study of cancer incidence in China, based on a retrospective survey of eighteen million deaths, found that 10.1% of deaths were attributed to cancer. Stomach cancer ranked highest among all cancers in China, followed by esophagus, liver, and lung cancer for males and cervix, esophagus and liver cancer for females. Compared with the world cancer incidence rate, China has the highest mortality rate from esophageal and nasopharyngeal cancers.

Generational differences in cancer incidence and mortality among Chinese immigrants have been examined. King and Haenszel (1973), in their comparison of cancer incidence among first and second generation Chinese Americans, found an overall decrease in mortality rates among second generation Chinese Americans for cancer of all sites. There was a decreased rate for nasopharyngeal, esophageal, stomach, liver and lung cancer for males and a decrease in stomach and breast cancer, but an increase in lung cancer, in females. They concluded that immigrant populations retain their predispositions for certain types of cancers, although the prevalence rates change over time. This is thought to be due to exposure to enviromental and cultural elements in the adopted country. King and Haenszel (1973), however, advise cautious interpretation of these data. They recommend that data be collected for longer periods of time to establish site-specific patterns of generational differences. Compared to the main-stream population, they found Chinese immigrants to have a decreased risk of prostate cancer and a higher rate of nasopharyngeal, liver, and esophageal cancers for males and a decreased rate of breast and increased rate of lung cancer for females. Zhang, Maclennan and Berry (1984), in their study comparing foreign-born Chinese with Australians (which included Australian-born Chinese), found the lung cancer rate among foreign-born Chinese to be significantly higher than that of Australians, especially in females. Stomach cancer was found to be two and a half times higher in both sexes and breast cancer was found to be lower among foreign-born Chinese females than those born in Australia. Wang, Ramcharan and Love (1989), using data from Statistics Canada from 1980 to 1984, found differences in cancer incidence among foreign-born Chinese compared to Canadian-born Chinese. While cancer of the gall bladder, liver and nasopharynx were among the ten leading cancer sites among Chinese males and females, these cancer sites are absent from the top ten cancer sites for Canadian-born Chinese (Wang, Ramcharan & Love, 1989). Also, the mortality rate from breast cancer was significantly lower in foreign-born Chinese females compared with Canadian-born Chinese females.

Cross-cultural comparisons of cancer mortality and morbidity have been researched. Yu (1991) examined data from SEER (The Surveillance, Epidemiology, and End Results), a continuing project of the National Cancer Institute in the United States since it began in 1972. He compared data from SEER and the Cancer Registry at the Shanghai Tumor Institute and found that between 1968 and 1981, cancer of the colon, rectum, prostate and breast were consistently highest among Americans, followed by Chinese Americans. The lowest rates were among Chinese in China. They hypothesized that enviromental factors such as diet may account for the differences in cancer incidence. Similar findings were observed by Stellman and Wang (1994). Yu (1986) studied the health of Chinese elderly in America using data from NCHS (National Center for Health Statistics) which includes data from SEER and information from birth records and death certificates. He found the overall cancer incidence rate much higher for White Americans than for Chinese Americans. When examining the site-specific cancer rates, however, he found nasopharyngeal, gastrointestinal, and liver cancer much higher for the Chinese, and the incidence of skin, genital and breast cancer lower among the Chinese (Yu, 1986). Olsen and Frank-Stromborg (1993) also found that data from the National Cancer Institute, supported the finding that liver cancer among Chinese Americans significantly exceeds that of white Americans.

Canadian Cancer Statistics (1996) reported that the three highest cancer mortality rates for men in Canada are lung, prostate and colorectal cancer and for women in Canada are lung, breast and colorectal cancer. This is quite different from what is found in China. In China, the highest cancer mortality rates are related to stomach, esophagus, liver and lung cancer for men and cervix, esophagus and liver cancer for women. The incidence of breast cancer, while found to be low in China, is high among Canadian women. The breast cancer rate in Canada ranks second highest in the world, exceeded only by that found in the United States and followed by those of the Western Europe countries (Canadian Cancer Statistics, 1993). Luo, Birkett and Mao (1998) compared Canadian-born Chinese, Chinese immigrants in Alberta, and Shanghai Chinese using age-standardized (world population) incidence rates and found cancer of the nasopharynx, stomach, and liver to be much higher among Shanghai Chinese, followed by Chinese immigrants. The lowest rate was found in the Canadian-born population. On the other hand, cancer of the breast was found to be lowest among Shanghai Chinese and highest among the Canadian population with Chinese immigrants' rates being in the middle. Nasopharyngeal cancer is highest among Chinese immigrants in Alberta, followed by Shanghai Chinese and then the Canadian population while lung cancer is similar among Canadian and Shanghai Chinese and slightly lower in Chinese immigrants.

Tracking cancer incidence and mortality rates of Chinese immigrants is difficult because of the relatively small population. Meaningful data were not available until recent years when Chinese immigrant numbers increased. A potential problem of these studies is the use of information on death certificates and on information regarding ethnicity and birth place. Yu (1986) questioned the accuracy and the completeness of these informations. A degree of caution is necessary when interpreting these data. One way to get accurate cancer statistics is by using multiple data sources.

Canadian cancer statistics come from multiple data sources: The National Cancer Institute of Canada; Statistics Canada; Health Canada; provincial/territorial cancer registeries; and, the offices of Vital Statistics. In Alberta, all cancer diagnoses are reported to the Alberta Cancer Registry. There are currently two major cancer centers in Alberta that provide the majority of cancer treatments and follow up. These two cancer centers are the Cross Cancer Institute (CCI) in Edmonton and the Tom Baker Cancer Institute in Calgary. There are, in addition, a number of satellite cancer clinics located in small urban centres throughout Alberta.

When patients are referred to the cancer clinics, demographic data including birth place are collected (personal communication with CCI, 1998). This information, however, is not always complete. Patients' language preferences are sought for the purpose of arranging for interpreters when there are language barriers. If patients are relatively fluent in English, English is recorded as their language of preference. Since language use does not always correspond with birth place, the number of Chinese immigrants who have cancer in Edmonton is difficult to determine.

Previously mentioned studies found cancer incidence rates among Chinese immigrants in North America varied according to cancer sites and these rates change as this population progresses to the second or third generation, suggesting an interplay between environment and genetics. Available information indicates that cancer is a significant problem among Chinese immigrants. Morbidity and mortality rates are high for some cancers despite advances in treatments. Current cancer treatments include surgical resection, chemotherapy, radiation therapy and biotherapy. These treatments are used either individually or in combination to optimize survival rates and to enhance quality of life. The effectiveness of the treatments cannot be guaranteed. In addition, these treatments can produce devastating side effects such as nausea, vomiting or disfigurement. When patients are presented with treatment choices, they need to consider the potential for improved life expectancy as well as their ability to manage the side effects. These considerations must be made for each of the treatment options offered to them, making the decision-making process highly complex.

Making Cancer Treatment Decisions

Making cancer treatment decisions requires a great deal of mental energy. When first confronted with the cancer diagnosis, the level of distress is often great (Baider, Kaufman, Ever-Hadani, & De-Nour, 1996; Chaturvedi, 1994; Frank-Stromborg, Wright, Segalla, & Diekmann, 1984; Martinson, Su & Liang, 1993; Ngan, Tang & Lau, 1994; Van Servellen, Sarna, Padilla, & Brecht, 1996; Verma & Asthana, 1994). Chaturvedi (1994) found that patients diagnosed with advanced cancer experienced anxiety and depression, and expressed concerns about cancer pain, physical health, not being able to work, finances and the future. Baider et al. (1996) found that a cancer diagnosis added to new immigrants' stress, increasing their vulnerability. Frank-Stromborg et al. (1984) studied patients' responses to cancer diagnosis, using questionnaires to collect data from 340 patients. Forty-five percent of their respondents reported experiencing shock, fear and disbelief, anger, depression and hopelessness. Less than a third (27%) of the patients expressed positive responses such as feeling relieved, acceptance, viewing the cancer as a challenge, and wishing to get on with treatments. Some patients expressed concern about how cancer might impact their financial status and their family and some patients exhibited denial. It is clear that a cancer diagnosis can cause a multitude of reactions in patients.

The consumer movement in the last few decades has encouraged increased involvement in health care decisions by patients. Giving information to patients and allowing them to be actively involved in treatment decision-making is thought to encourage patients' control over their own lives. A number of studies have examined patients' preferences in treatment decision making and the factors that influence their decision making preferences.

Cancer Treatment Decision-making Preferences

Considerable research has focused on patient decision making preferences. Degner and Sloan (1992) studied the role people actually want to assume in selecting cancer treatment. They found that 59% of patients wanted their physicians to make treatment decisions on their behalf and only 12% of patients preferred to play an active role in decision making. In this study, the researchers used a card sort technique to collect data (Appendix G). This method is a modification of the method used in previous studies. These studies used simple statements that implied yes and no, which oversimplified the process of decision making. (Blanchard, Labrecque, Ruckdeschel & Blandchard, 1988; Cassileth, Zupkis, Sutton-Smith & March, 1980). The card sort measurement technique provides a range of decisional control scenarios, including total control by the patient, collaborative decision-making with the physician, and total control by the physician. These scenarios are better representations of the patient's viewpoints and more closely resemble real life situations than the yes and no scenarios. Some researchers (Beisecker & Beisecker, 1990; Beaver, Lukar, Owens, Leinster & Degner, 1996; Davison Degner & Morgan, 1995; Siminoff & Fetting, 1989; Sutherland, Lliewellyn-Thomas, Lockwood, Trichler & Till, 1989) have found that the majority of patients desire a relatively passive role whereas other researchers (Blandchard, et al., 1988; Cassileth, et al., 1980; Degner & Russell, 1988; Ende, Kazis, Ash & Moskowitz, 1989; Hack, Degner & Dyck, 1994) have found that some patients desire to have some control in decision making. There are a number of possible explanations for these apparently discrepant findings. Degner and Sloan (1992) compared people who are facing the actual cancer diagnosis with people who are given a hypothetical situation and found significant differences in their decisional role preference. They found that when presented with a hypothetical diagnosis of cancer, respondents were more likely to select active decision-making control whereas respondents who were facing the actual diagnosis of cancer tended to want to rely more on their physicians and so selected somewhat more passive decision-making roles for themselves.

Demographic Variables and Decision-making Preferences

Education has been proposed as a potential influence on decision making preferences (Cassileth et al., 1980; Degner & Sloan, 1992; Hack, Degner & Dyck, 1994; Haug & Lavin, 1981; Skrull, Lo & Charles, 1984; Vertinsky, Thompson & Uyeno, 1974). Degner and Sloan (1992) compared newly diagnosed cancer patients with the general public using questionnaires and found that patients who were more educated desired more decisional control. Casselith et al. (1980), Hack, Degner and Dyck, (1994), and Skrull, Lo and Charles (1984) reported similar findings. Vertinsky, Thompson and Uyeno (1974) observed that education, in combination with income and age produced significant effects, but that these variables individually did not provide sufficient explanation of patients' preferences. Haug and Lavin (1981) found that education and belief in consumerism affected decisional preferences. In other words, patients who believed in their right as a consumer in health care would demand greater decisional control, and people with more education tended to believe in consumers' rights and therefore desire to have more control in their health care decisions.

Siminoff and Fetting (1991) studied 100 breast cancer patients and physicians using audiorecording of the patient-physician interaction, post visit questionnaires completed by the physicians, and semi-structured interviews with the patients. They found that patients desire thorough and specific information about the disease and treatment options and potential benefits, and that more educated patients were more likely to participate in the decision making process. They suggested that people who have more education are more likely to understand the information given and therefore be more willing and able to participate in decision making. Patients who have less formal education tend to adhere without question to their physicians' advice.

Beaver, Lukar, Owens, Leinster and Degner (1996), using structured interviews, examined the decision-making preferences of 150 women newly diagnosed with breast cancer and 200 women diagnosed with benign breast diseases. They found education was not a predictor for decision-making preferences for either group. This study was conducted in the United Kingdom, whereas the studies which found education to be a predictor of decision-making preference were conducted in North America. Morever, their study is more recent than the other studies. Perhaps women in the U.K. are more likely to want a more active role in the decision-making process. It is possible that more recent studies of women in North America would result in similar findings. The inconsistency of findings linking education with decision-making preferences warrants further research.

Gender, age, social class and ethnicity have also been found to influence decision-making behaviour. Degner and Sloan (1992) found that females with reproductive cancers preferred more control than did their male counterparts and that older patients preferred less control than did younger patients. Cassileth et al. (1980) found older persons preferred less decisional control and that gender had no effect on decisional control. Hack, Degner and Dyck (1994) found older persons preferred less involvement in decision-making but did not study the influence of gender as all of their subjects were female. Skrull, Lo and Charles (1984) found younger persons more likely to engage in decision-making regarding their own care. Only two studies examined ethnicity and its influence on decision-making preferences (Cassileth et al., 1980; Skrull, Charles & Lo, 1984). Both studies found that Caucasians were more likely to want control in treatment decision-making than members of other races. Social class was found to affect decisonal preferences as well. People with higher incomes preferred more control in treatment decisions (Skrull, Lo & Charles, 1984). Beaver et al. (1996), in their U.K. study, correlated social class and age with decisional preferences. They found that for women with breast cancer, age had no impact on decision-making but that social class did have a significant influence. For the benign breast disease group, social class was not found to influence decisional preference but age was. These findings were significant but the effect was minimal and only accounted for 2% of the variance.

It seems that there is little agreement on which demographic variables influence decisional preference and whether that relationship is direct or indirect. Haug and Lavin (1981) said that beliefs about physicians' authority and accountability and patients' rights somehow influence patients' decisional preferences. Such beliefs may vary depending on education, age, social class, gender and ethnic background.

The Role of Information and Decision-making

The role of information in affecting patients' decision making has also been studied. Manfredi, Czaja, Buis and Derk (1993) conducted telephone interviews of 257 patients. Information was sought from the Cancer Information Service (CIS) by 49% of patients just after diagnosis and by 31% of patients during treatment. The information they sought from CIS included explanatory information about cancer and its treatment, treatment options, experimental treatments, ways to cope with treatment side effects, referral to community resources, and information on nutrition. The researchers suggested that since nearly 50% of the callers seeking cancer information were at an early stage of their cancer diagnosis and prior to commencement of treatment, that information must play a role in treatment selection. They concluded that information affects how patients make and cope with treatment decisions. A number of researchers (Cassileth et al., 1980; Chesser & Anderson, 1975; Greenberg, Jewell, Gluck, Champion, Leikin, Altieri & Lipnick, 1984; Herr, Kornblith, & Ofman, 1993; Lidz, Meisel & Munetz, 1985; Lliewellyn-Thomas, McGreal, Thiel, Fine, & Erlichman, 1991; O'Connor, 1989) found that the amount and specificity of information about treatment conveyed to the patient influences the acceptance or rejection of the physician's recommendations. They found that patients desired specific information on their disease, length of treatments, type of drug used, treatment side effects, survival rate and quality of survival time. Ward, Heidrich and Wolberg (1989) and Herr, Kornblith and Ofman (1993) found that patients consider information on treatment side effects and treatment efficacy in deciding treatment options. Herr, Kornblith and Ofman (1993), in their study of 35 men who were diagnosed with metastatic prostate cancer, found that their subjects used the information they received and considered how hormones might affect their sexual function and general well-being. They weighed considerations of quality versus quantity of life before choosing treatment options. Information, therefore, is found to relate to decision-making preferences.

Information Recall

Hughes (1993) studied women with stage 1 and 2 breast cancer. She found that a high percentage of participants who received information on their treatment options exhibited poor recall of information given. There are several possible explanations for the poor recall. It may be that these patients' anxiety levels had been too high for them to absorb the information or that anxiety inhibited their ability to recall. It could be that they simply did not understand the information presented and therefore could not recall it. It could also mean that they understood the information but were unable to recite it when asked. Poor recall neither automatically implies poor understanding nor does it suggest that information-giving is not a critical component of compassionate care.

Information Needs

In terms of patients' desire for information, Hack, Degner and Dyck (1994) and Beaver et al. (1996) found that both active and passive decision makers desired information on their diagnosis, treatment and side effects and ways to remedy the side effects. It seems that the majority of patients want to know as much as possible about their disease and possible treatment, regardless of whether or not they want to be involved in the final treatment selection. Other researchers have also observed that patients desire information about their disease and treatments but may not use this information to make treatment choices (Beisecker & Beisecker, 1990; Blanchard et al., 1988; Cassileth et al., 1980). These findings contrast with those of Herr, Kornblith & Ofman (1993) who found that patients desired specific information on treatment side effects and make treatment decisions based on the consideration of these side effects and how they may affect their quality of life.

Type and Source of Information Sought

Kalinowski (1991) said that the majority of women with breast cancer who gathered information before treatment began by reading lay or professional publications or by speaking to others who have had similar experiences. Lukar, Beaver, Leinster, Owens and Degner (1994) found that breast cancer patients placed more emphasis on information concerning the physical aspects of the disease such as extent of the disease, likelihood of cure and available treatment options and their side effects, and placed less emphasis on the treatment effects on their sexuality and image.

Davison, Degner and Morgan (1995) studied the information needs of 57 men newly diagnosed with prostate cancer and asked them to prioritize the types of information they needed. These men ranked information about how advanced their disease was and the likelihood of cure as their highest need. Effects of treatment on usual sexual activity was ranked lowest. This finding seems to contradict the findings of Herr, Kornblith and Ofman (1993). The explanation is found in the differences in the sample. Davison, Degner and Morgan's sample was men newly diagnosed with prostate cancer and their focus was on treatment to cure. They were less concerned with sexuality at the time. Herr's sample was men with metastatic disease and the focus of treatment was to prolong life. Their concern was on the quality of life for the time they had left and this quality of life included concerns about sexual functioning.

Lukar et al. (1994) found that women with breast cancer prioritize their information needs in a manner similar to the men in Davison, Degner and Morgan's (1995) sample. Women ranked information on altering bodily image and sexuality lower than information on cancer and the treatment. Ranking information about sexuality at the bottom of the list does not imply that respondents consider sexuality to be unimportant. It really means that patients prioritize the kind of information they want at different stages of their illness. Lukar et al. (1994) suggested that patients' information needs may vary at different stages of their disease progression, but this has not been studied.

Information Giving and Receiving

Information giving and receiving often occurs during physician/patient interactions. Street (1991) has suggested that the amount of information physicians give their patients is strongly influenced by the patients' communicative style and by the patients' personal characteristics. She found that through their communication style, patients can exert control over the amount of information they receive from the physician and that extremely anxious patients may receive less information than patients who appear calm. This study suggests that by controlling the expressions of anxiety, patients may be able to elicit more information from their physicians. However, Beisecker and Beisecker (1990) studied 106 patients and 7 physicians using questionnaires and audio-tapes of physician-patient interactions. They found that despite the patients' stated desires to know more about their medical situations, that desire for information was not uniformly expressed during physician/patient interactions. These findings suggest that patients may not know how to elicit the desired amount of information from physicians during their appointments with them. In turn, physicians may not know how to assess their patients' informational needs and preferences.These studies suggest that patients' and physicians' communication styles may influence information sharing.

The Benefit of Information

Some studies support the importance of information in treatment decisions which may lead to better health outcomes. Greenfield, Kaplan and Ware (1985) found that patient participation in treatment decisions resulted in improved physical functions. Fallowfield, Hall, Maquire and Baum (1990) and Morris and Royle (1988) found that patients who participate in decision making exhibited less anxiety and depression than did patients whose participation was minimal, and that having sufficient information enhanced their decision-making ability. Neufeld, Degner and Dick (1993) state that information seeking can offer patients a sense of control and enable them to participate in discussions about treatment alternatives. This may generate the commitment needed to sustain further actions.

Culturally Based Views on Information Dissemination and Decision-making about Treatments

There are many cultural variations in information dissemination and decision-making preferences in health care. These variations may be due to the individual culture's values and beliefs on health and illness, and the cultural belief regarding interpersonal relationships within families and with health care professionals (Chen, 1996; Kuo & Kavanagh, 1994; Kleinman, 1980; Lee, 1975; Lin, Milton, Poland, Nuccio & Yamaguchi, 1991; Louie, 1985; Muller & Desmond, 1992; Shih, 1996; Yeo, 1995). These variations involve how and what information is sought, who will seek that information, and what will be done with that information as it relates to making health care decisions.

A number of studies have explored culturally-based views on the dissemination of information. Such views focus on who should be the initial recipient of news of a cancer diagnosis, and what information should be provided to patients or withheld from them. Blackhall, Murphy, Frank, Michel and Azen (1995) found that Korean

Americans are less likely than African and European Americans to believe that patients with metastatic cancer should be told the truth about their diagnoses. Desire for information varies with other cultures as well. The Navajo culture emphasizes the importance of positive thinking and perceives that disclosing negative information may cause harm to patients (Carrese & Rhodes, 1995). As a result, physicians are advised to tell only good news to patients.

Cultural views on the dissemination of information also focus on who should be responsible for making health care decisions. Korean Americans have expressed the belief that family members should make decisions regarding life prolonging technology. Kleinman (1980), in a study of Chinese patients in Taiwan, found that the family is seen as most responsible for making health care decisions and information about the sick person is given to the family but withheld from the patient. This family involvement model is also shared by other cultural groups such as Ethiopian, Chinese, Korean, Mexican and Filipino Americans (Beyene, 1992; Klessig, 1992; Muller & Desmond, 1992).

In terms of interaction with physicians, Kleinman (1980) observed that Chinese doctors interact minimally with their patients and that Taiwan Chinese patients do not ask questions about their illness. He believes that the traditional Chinese culture, which enforces politeness and subservience in the presence of "superior" individuals, is the reason for this behavior. He also found that the doctor-patient relationship is normally one of distance and that patients are taught not to challenge physicians even when they disagree with them. Kleinman (1980) cautioned that this finding may apply only to the subjects in his study and that different findings might have been obtained had he studied American Chinese persons or people from Mainland China. While Kleinman (1980) made some interesting observations on physician-patient interactions in Taiwan in the 1970's, it is unclear whether similar observations would be found among Canadian Chinese immigrants in the late 1990's.

Few studies have focused on Chinese immigrants in general and fewer studies still have focussed on Chinese cancer patients. In particular, Chinese cancer patients' perceived information needs and role preferences in cancer treatment decisions have not been studied. Despite the abundance of literature in studying decision making, the Chinese-Canadians' experiences have not been examined.

Qualitative versus Quantitative Methods

Much of the research on decision-making preference and information needs (Beaver et al., 1996; Beisecker & Beisecker, 1990; Blandchard et al., 1988; Davison, Degner & Morgan, 1995; Degner & Sloan, 1992; Hack, Degner & Dyck, 1994; Herr, Kornblith & Ofman, 1993) is quantitative as is the research on Chinese people who suffer cancer (Dodd, Chen, Lindsey & Piper, 1985; Fielding, Ko & Wong, 1994; Lindsey, Dodd & Chen, 1985; Ma, 1996).

Brink and Wood (1989) said quantitative and qualitative research differs in the methods of data collection and in the types of data collected (p.12). When little is known about a population, an exploratory qualitative study is appropriate. The method of data collection is by open-ended interviews and the types of data collected would be quotes from the interviews. Qualitative methods have the potential to produce interesting findings as open ended interviewing requires patients to explore their thoughts and to express their opinions freely and allows for exploration of variables in a population. As a result, richer information can be obtained. Choosing an exploratory study design to examine Chinese cancer patients' decisional preferences and information needs has the potential to yield deeper understanding of needs in this population.

Pierce (1993) studied women with breast cancer using qualitative data with the intent of building more structured research upon it. It was a qualitative study using semi-structured interviews to collect data. She studied 48 women who were diagnosed with breast cancer and asked them to describe how they think through their decisions. She found three decision-making styles: deferrer, delayer and deliberator. The deferrers are those patients who are attracted to one option immediately and choose that option without experiencing conflicts. The delayers consider at least two options and vaccilate between options, experiencing some stress and difficulties in making decisions. These women typically sought information from non-technical sources.

Deliberators express personal responsibility, seek information purposefully, and experience moderate amounts of stress. Pierce (1993) recommended further study of women's satisfaction with the decision outcomes and suggested further work in fashioning different supports for these women to suit their decision-making styles. This study adds to the knowledge about women who are making treatment decisions and more research can be built upon it. Similarly, qualitative descriptive research on the Chinese population has the potential to yield valuable baseline information on which more research could be built.

Reflections on the Literature

Cancer treatment decision making is a well studied area. The existing literature has uncovered a range of factors that influence treatment decision making. Age, gender, education level, social class, ethnicity and the role of information have been examined. As treatment decision-making is part of the illness experience and that illness experience is shaped by individual cultures, the Chinese cancer patients' experiences may have unique facets.

As little is known about Chinese immigrants in Canada who suffer from cancer, a qualitative study to examine information needs and decision-making preferences in this population was conducted. The research approach is described in the next chapter.

Chapter 4

THE RESEARCH PROCESS

A qualitative descriptive study using the ethnographic interview technique was conducted in order to gain deeper insight into the cancer experience of Chinese immigrants to Canada. Since there is limited information about this population, a descriptive study has the potential to yield rich and broad based information. The interview data obtained is emic in nature, that is, from the participant's perspective (Field & Morse, 1985). Tesch (1990) states that the main purpose of ethnographic analysis is to achieve deeper insight, to search for commonalities across the study participants or sites, to explore uniqueness, and to interpret the meaning of the discovered pattern. Spradley (1980) says much of any culture is encoded in linguistic form and greater understanding of a culture can be achieved by listening to what people say. The intent of this study was to gain some basic information about the Chinese-Canadian population so that further studies and interventions could be developed.

Research Questions

While the following research questions were generated when the proposal was developed, the scope of the data collected went beyond the initial intent. The original research questions were:

1. What information needs do Chinese-Canadian cancer patients perceive in relation to their diagnosis, treatment and prognosis?
2. What understanding do these patients have of the verbal and /or written information given to them regarding treatment options?
3. What decision-making roles do Chinese-Canadian cancer patients prefer?

Selection of Sample

For this study, Chinese-Canadian cancer patients were defined as persons who have immigrated to Canada, who identify themselves as of Chinese origin, and whose first language is Cantonese. Participants were selected using the purposeful sampling technique. Field and Morse (1985) state that, by using the purposeful sampling strategy, the researcher selects participants who have specific characteristics and who meet the study's need. Ten participants were chosen within nine months. The criteria for participation were stated in the original proposal as:

1. First time diagnosed cancer patients, with or without surgical interventions, who were referred for further treatment options.
2. Individuals who had received an initial diagnosis of cancer (any type) within six months of participation in this study.
3. Individuals who speak Cantonese as their first language.
4. Chinese-Canadian individuals who were born outside of Canada.

Participation was solicited in three ways: from family physicians; through advertisement at the Chinese Community Service Centre (CCSC); and through advertisement with one of the local Chinese newspapers. Information letters to the physicians (Appendix A) were delivered by the researcher in person. Verbal explanation accompanied distribution of the information letters whenever possible. The information sheet to the prospective participants (Appendix B) and the advertisement (Appendix C) were translated into Chinese. The information sheet was given to the potential participants by physicians or staff at CCSC. The invitation advertisement was posted at CCSC and printed in one of the local Chinese newspapers.

As solicitation of participants was difficult, some modifications were made to the initial inclusion criteria. For example, there was no response from the newspaper advertisement. Twelve physicians were contacted between January and June and only four participants were recruited from that source. A decision was made to include participants who did not fit all inclusion criteria. For example, one participant had two prior experiences with cancer. While all participants were referred to the same cancer institute, three participants were not offered additional treatment following surgery. Another participant chose not to have radiation treatment. For these participants, the exploration of treatment decision-making focused mainly on types of surgery.

Description of Sample

It took nine months to recruit ten participants. Eight of the ten participants were recruited by referral from physicians and two from CCSC. Although the Chinese newspaper advertisement ran for three months, no participants were recruited from this source. All participants were born outside of Canada. Countries of origin included; Hong Kong (4), China (3) , Macau (1), Vietnam (1) and Taiwan (1). The participant who was born in Vietnam returned to China to live in 1978 and the participant who was born in Macau was raised in Hong Kong. All participants spoke Cantonese and one also spoke Mandarin. Ability to speak and comprehend English varied with participants, with those from China and Vietnam exhibiting most difficulty in verbal and written English. One participant was fluent in English whereas four were able to communicate in simple English but verbalized limited ability to comprehend materials written in English or to write in English.

Age of participants ranged from 45 to 71 years with a mean age of 57. The sample included seven women and three men. Length of residence in Canada ranged from 4 months to 35 years with a mean of 12 years. Education of participants ranged from 5 to 18 years with a mean of 11 years. All participants obtained their formal schooling in their native country. The inclusion/exclusion of English as one of their school subjects varied. One participant lived alone, six participants lived in nuclear families, and three participants lived in extended families. The cancer histories of participants are presented in Chapter Five.

Data Collection

Data were collected using the ethnographic interview technique. Each participant was interviewed twice. All interviews were conducted in Cantonese, but one participant chose to converse occasionally in English during the two interviews. During the first interviews, consent forms (Appendix D) were signed and demographic data and cancer histories (Appendix E) were completed. Several semi-structured questions (Appendix F) were asked during the first interview. The interviews were guided using semistructured questions to ensure compatibility across participants but exploration of other issues of concern to participants also was encouraged.

Second interviews were scheduled within three to nine weeks of the first interview, depending on the availability of participants. During the second interview, participants were asked to validate and expand on the information provided in the first interview. A card sort technique (Appendix G), aimed specifically at gaining information on how the participants saw themselves as decision makers regarding their cancer treatment, was introduced in the second interview. The card sort technique for discerning decision-making preferences of cancer patients was first introduced by Degner and Russell (1988), was modified to its current form by Degner and Sloan (1992), and has been used repeatedly by other researchers (Davison, Degner & Morgan, 1995; Neufeld, Degner & Dick, 1993; Beaver, Lukar, Owens, Leinster, & Degner, 1996). It has not been used, however, in the Chinese-Canadian population. Permission for its use was obtained (Appendix H).

Five cards were used in Degner and Sloan's research. These cards read as follows:

A. I prefer to make the final selection about which treatment I will receive.

B. I prefer to make the final selection of my treatment after seriously considering my doctor's opinion.

C. I prefer that my doctor and I share responsibility for deciding which treatment is best for me.

D. I prefer that my doctor makes the final decision about which treatment will be used, but seriously considers my opinion.

E. I prefer to leave all decisions regarding my treatment to my doctor.

The statements on the cards were translated into Chinese (Appendix G) and participants were asked to read either the Chinese or English versions. Participants were asked which of the written statements best described their decision-making preference for determining cancer treatment options. Two participants chose to use the English version. Three participants required the researcher to read the statements in Chinese as they had limited reading skill in Chinese. Five participants read the Chinese version. All interviews were audio taped then transcribed and translated by the researcher. How translation was handled will be described later in this chapter in the section on research standards.

In addition to interviews, the researcher recorded observations about the interview contexts in field notes. Spradley (1980) has suggested that field notes should include space, actor, activity, object, act, event, time, goal and feeling. A journal was kept in which my feelings over the course of data collection and analysis were recorded. Some of this information became valuable as a source of data. Reviewing the journal gave insight into what questions to ask during the second interviews. Memos were used to record the progress of the research, including keeping track of which physician to contact, recording when participants became available for interviews, and developing insights regarding the data as data collection and analysis progressed. It was a way to keep on track and to avoid what Hemmerley and Atkinson (1983) described as "aimless drifting through data" (p.165). Keeping memos and a personal journal allowed for better organization of the research process.

Field Research Issues

There are issues and difficulties that surround field research. The greatest difficulty lay with recruiting participants. There was no response from the newspaper advertisement. Two participants were recruited through the Chinese Community Service Centre and the other eight were recruited through physicians. Four others were contacted but did not participate either because they did not fit the inclusion criteria or, once the research was explained, they chose not to participate. Reasons for exclusion were: born in Canada(1); diagnosed for more than two years(1); refusal to participate(1); and, moving to another province to be with family(1).

There was difficulty getting physicians to agree to refer patients for the study. Physicians were visited in their office and the purpose of the study was explained.

Much time was spent waiting for the physician to finish patient visits despite having an appointment. Physicians were to call if eligible prospective participants were found. Some physicians were willing to assist and showed great interest. Others would not listen to the details of the study. Twelve physicians were approached and six agreed to help. Four physicians suggested participants.

Another difficulty was mechanical failure. In one interview, the tape recorder malfunctioned and the interview had to stop. In another interview, the audio-tape was blank and the interview was repeated. Overall, the people who participated were quite willing to do so. Due to low energy levels, however, some chose to have shorter interviews. Sometimes family members would participate or add comments. The second interview often yielded better data as the participants were more comfortable with the researcher. Each hour of interview required four to five hours of translation and transcription.

Analysis of Data

Miles and Huberman (1994) described data analysis as consisting of three themes; data reduction, data display, and conclusion drawing and verification. The data from this study came from three different sources; the interview data (including card sorts), the memos that the researcher kept, and the observational information. Multiple data collection provides richer information. The majority of data came from the interviews. Each participant was interviewed twice. The recorded interviews were translated and transcribed.

Strauss and Corbin (1990) described coding as "the part of the analysis which includes naming and categorizing of phenomena through close examination of data" (p. 62). There are two approaches to examining the data set. One approach is cross-case analysis which is to compare data of different cases or participants, looking for similarities and differences. The other approach is variables-oriented in which chosen variables among the participants are examined. As Miles and Huberman (1994) suggest, both approaches were used in analysing the data in this research.

As described by Strauss and Corbin (1990), data analysis was divided into three distinct operations. The first step was to analyse the data in an attempt to answer the research questions. This step included coding and naming the data, grouping it into themes, and examination of the participants' preferences on the card sort. The second step was to analyse the emerging themes that were shared by the participants. Although not the initial objectives of the study, the participants spoke about their belief in TCM and voluntarily expressed how cancer has impacted their lives. These emerging patterns of information were of significant importance and yielded valuable information about this group. It was during this step of the analysis that the importance of the literature review presented in Chapter Two was recognized. The third step required analysis of findings of steps one and two in relation to existing knowledge.

Field and Morse (1985) suggest the cut and paste method to manage a smaller data set and this procedure was chosen for this research. Data were coded according to their meaning within the context of the interviews then grouped together to form themes. The emerging themes were then examined for their interconnectedness. Different themes were grouped together to form concepts. The researcher then returned to the data and examined segments of each for fit with emerging patterns. Field notes and memos gave additional meanings as the context of each interview was recorded as well as thoughts and insights gained during data collection or translation and transcription of videotapes.

Ethical Considerations

Ethical concerns such as informed consent, confidentiality, anonymity, nonmalificence, and beneficence need to be addressed. Approval to conduct the study was received from the Ethics Committee, Faculty of Nursing (Appendix I) prior to initiation of data collection.

Informed Consent

Lipson (1994) states that the principle of informed consent is important in any type of human research. A consent form (Appendix D), translated into Chinese, was presented to participants at the first interview and was read to them in Cantonese. The participants were then asked if they understood what was read. In order to ensure true understanding of the consent form, each participant was asked to describe what was in the consent form. All participants demonstrated understanding and signed the form. A copy of the consent form was left in each participant's home.

Confidentiality and Anonymity

Participants were given pseudonyms to protect their identities. The participants' names and demographic data were safeguarded and only the researcher has access to them. Any identifying data, such as the participants' true ages or physician's names, were omitted to protect the anonymity of the participants. The Edmonton Chinese community is relatively small and the physicians are known to the Chinese community. This will prevent patients being identified by naming their physicians. All interview data were treated with care and for most interviews only the co-supervisors had access to the transcribed raw data. The exceptions occur because of the procedure used to validate translation that is described in the section on credibility in research standards. All audiotapes and information are stored in a locked filing cabinet.

Nonmaleficence

It was the researcher's responsibility to be sensitive to the participants' emotional states and energy levels (Cowles, 1988). The interview times were flexible to suit the participants' preferences. The interview times ranged from 30 to 80 minutes. Cancer is a sensitive topic. During interviews, some strong emotions were evoked. At such times, an offer to stop the interviews was made if participants wished. One participant did terminate the interview but agreed to a second interview. Another participant reported having such emotional arousal that she had problems sleeping for a few days afterwards but still agreed to a second interview. One participant had such difficulty in her surgical experience and had suffered so much pain that she agreed to a referral to a massage therapist. Psychological counselling was not offered as it was clear that such was not desired by the participant. Others reported not finding it to be particularly traumatic when describing their experiences. When family were around and if the patient agreed, the family's participation appeared to be helpful in easing anxiety. Only two participants' families were present for interviews. In both cases, the family members were involved in only one interview.

Beneficence

While there was no obvious benefit to the participants, the opportunity to discuss feelings related to the cancer experience may have been helpful. All were offered a summary of the research findings but none expressed interest. There were requests to obtain information and to make a doctor's appointment. This assistance was provided at the end of the interviews. No further contacts were made with the participants once data collection was completed. One of the participants indicated that I was the only person with whom she had discussed her cancer. As Ford and Reutter (1990) describe, relating their experience to others may heighten their awareness of that experience and may result in positive emotional outcomes. During data collection, I was received well by the participants.

Data Disposal

The data are secure at the University of Alberta. As required by university policy, it will be stored under lock and key for seven years and then destroyed.

Research Standards

According to Sandelowski (1986) there are four criteria for evaluating rigour in qualitative research; credibility, fittingness, auditability and confirmability. Efforts were made to achieve these criteria.

Credibility

The true value of a qualitative investigation "resides in the discovery of human phenomena or experiences as they are lived or perceived by subjects" (Sandelowski, 1986, p.30). I share the same language and cultural background with the participants and that enhanced the understanding of their life experiences and the words they used. Van Manen (1990) and Twinn (1996) discuss language and culture as important factors influencing the validity of findings. Twinn (1996) further suggested that having one translator for all the interviews enhances consistency within the data. Credibility is achieved when the experience is described faithfully so that the person reading it would "recognize it as their own" (Sandelowski, 1986, p. 30). During the second interview, I shared the transcript of each participant's first interview for validation, clarification and interpretation to ensure that the experience was understood. Participants were encouraged to use this opportunity to clarify, expand or provide alternative information. In addition, participants were contacted by phone if further verification was required.

Another way to ensure data accuracy for this study was to validate translated data. This was done in two ways. Another bilingual person read the first two transcripts while listening to the audio-tapes to ensure the accuracy of transcription and translation. Accuracy is achieved when the meaning of the dialogue is captured but not directly translated word by word. This method of translation is described by Fullerton, Wallace and Concha-Garcia (1993) as achieving equivalent representations of content and by Jones and Kay (1992) as symmetrical translation which aims at preservation of meaning and ideas. Then segments of the interviews of the first two participants were transcribed into written Chinese before being translated back into English by the second bilingual person. The two English versions (one done by the researcher and one by the independent person) were then compared to see if the meaning remained the same. These efforts ensured the accuracy of the translations and transcriptions for the first two interviews. As discrepancies were few, an assumption of accuracy was made for the remaining interviews. The bilingual collaborator was a professional with an understanding of the importance and meaning of confidentiality.

Fittingness

Sandelowski (1986) states that fittingness (applicability) occurs when " the findings can fit into a context outside the study situation and when its audience views the findings as meaningful and applicable in terms of their own experience" (p. 34). Seven out of ten participants had breast cancer which yielded more representative data for the breast cancer group. In examining the data, one looks at similarity with the current literature as well as examining the data that do not fit. Sandelowski (1986) suggests that the researcher to try to deliberately discount or disprove a conclusion so as not to interpret prematurely.

Auditability

Auditability refers to the repeatability of the study by another researcher (Sandelowski, 1986). Detailed records of the steps for analysis and of the decisions made were kept so that other researchers could follow the decision trail used in this study. The research process was written clearly in the report in order to facilitate auditability.

Confirmability

Confirmability refers to research findings that truly represent the participants' experiences. Interview data were validated with the participants to ensure they truly represented what they said. Use of interview data as well as memos and observational data add credibility to the data for achievement of confirmability. Sandelowski (1986) states that confirmability is achieved when auditability, truth value and applicability are achieved.

Reflections

The interviews with participants were rewarding. I felt a connectedness between myself and the participants and at times it was difficult to separate my feelings and objectively hear what they were telling me. At times it was emotionally exhausting. It is a general belief that the Chinese population is reluctant to disclose personal information, especially when it involves discussing their illnesses or other private matters. My encounter with them has demonstrated otherwise. The participants were quite open in sharing thoughts and feelings. It is possible that sharing the same ethnic background and understanding their language was instrumental in allowing them to express thoughts and feelings more freely.

The participants came from a variety of backgrounds and their thoughts and feelings differed. Yet there were similarities among them. There were also more similarities between them and the main-stream population of cancer patients as described in the literature than was expected. I was more surprised at the similarities with what is reported in the literature about North American cancer patients than at the differences. The findings are outlined in the next two chapters.

Chapter Five

THE CANCER EXPERIENCE OF CHINESE IMMIGRANTS

The aim of this study was to explore Chinese-Canadian patients' information needs and decision-making preferences when confronted with a diagnosis of cancer. From my experience as an immigrant from Hong Kong, as well as my knowledge of the literature on the health beliefs and experiences of Chinese immigrants in North America, I had certain assumptions about what I would find. The data, however, revealed more similarities than differences between Chinese-Canadian cancer patients and what has been reported in the literature regarding cancer patients in the mainstream populations in Canada and the United States. Furthermore, there were intergroup variations among the Chinese-Canadians with regard to their utilization of TCM and their perceptions of encounters with the Canadian health care system.

The findings will be described in two chapters. In this chapter, discussion will focus on an overview of the participants. Experiences with the course of the disease from diagnosis to treatment, including interactions with the health care system, will be described. Decision-making preferences will be explored.

Who Participated?

While a brief description of the participants was given in Chapter 4, more details will be given here. To enhance clarity, a table depicting characteristics of participants has been developed. In Table 1, each key participant's name, age, number of years in Canada, months since diagnosis at the time of the first research interview, financial situation, skill in English, and decision-making preference is given. Anglophone pseudonyms were chosen to facilitate gender identification as Chinese names are often unknown to North Americans. The decision-making preference reported in Table 1 refers to the content of the descriptive statement that was chosen, using the card sort technique designed by Degner and Sloan (1992).

Table 1

Participants' Characteristics

Pseudonym	Age	Years in Canada	Months since diagnosis	Financial situation	Skill in English	Decision-making preference
JEAN	50's	>20	5	self-employed	requires interpreter	doctor
PETER	70's	6-10	9	children support	requires interpreter	doctor
TINA	60's	11-15	1	retired	requires interpreter	doctor
JOHN	60's	1-5	4	children support	requires interpreter	doctor
PAUL	60's	1-5	6	children support	requires interpreter	doctor
SUSAN	70's	6-10	9	retired	requires interpreter	doctor
JANET	40's	11-15	5	spouse support	able to speak simple English	self
LISA	40's	11-15	11	self-employed	requires interpreter	doctor
LOUISE	50's	11-15	3	self-support	able to speak simple English	self
JOAN	40's	>20	10	self-support	fluent in English	doctor

Cancer History

Seven out of ten participants had breast cancer. The other three had malignant myeloma, stomach cancer and skin cancer. The seven people with breast cancer were female and the other three were male. Three out of seven breast cancer patients had mastectomies, one of whom had bilateral mastectomies with radiation to follow. Four of the seven women had lumpectomies with radiation. One of the ten participants had no surgery and six of the ten had radiation. One person received oral chemotherapy with no surgical resection. Nine out of ten people had surgery. One person received hormone therapy following radiation. All women had lymph nodes removed and were negative. All participants were referred to the same cancer treatment institution at some time during their illness.

Demographic Information

Socioeconomic status varied among the participants. The people who immigrated more recently and/or who are dependent on their children for financial support appeared to have the greatest financial hardships. Two women participants work outside of the home, two assist their husbands who are self-employed, and the remaining three women and three men do not work outside of their home. Social support is good among the participants. All have children and relatives for financial and emotional support even though they may not share the same residence. The Chinese Community Service Centre and the Chinese church provide additional support.

Family Composition and Previous Cancer Exposure

Three out of ten participants live in an extended family. This is common among immigrant families. All participants had prior exposure to cancer, either from family members having had cancer or from friends who have had cancer. Therefore, they had some knowledge of cancer before their own diagnosis.

The Cancer Experience

Making the Diagnosis

When asked how the cancer was discovered, participants described a variety of experiences. JEAN, SUSAN and LOUISE had similar experiences of discovering a lump and consulting their physician. LOUISE's description is typical:

> I found the lump in my left breast in April when I was in the shower. I went to my family doctor. He sent me to the breast centre for a check-up. I had a mammogram and biopsy.

Upon finding the lump, these women went to their physician for investigation. While some people further investigated what they found, others chose to ignore the first sign. PETER described his experience:

> This lump (around my nose) had been there for a long time. It looked like a scar, sometimes I picked at it and it went away. For two to three years I had this lump.

Others discovered their cancer accidentally:

> I really didn't feel unwell. I found out quite accidentally. My doctor sent me for mammography. He did do an examination but couldn't find it. So he said just do the mammography. (LISA)

JANET and JOAN discovered their breast cancer by routine mammography. TINA, upon finding out that a relative was recently diagnosed with breast cancer, asked her physician for a check up. The abnormality was discovered on the mammogram. A repeat mammography confirmed the diagnosis six months later.

JOHN and PAUL shared experiences that differed from those of the other participants. Both were under medical investigation prior to coming to Canada. Their investigations were stopped because their designated time to emigrate was near. They were investigated further upon arrival in Canada and JOHN's cancer was found after extensive testing. PAUL was less fortunate. His cancer was not diagnosed until he was in the hospital for treatment of an unrelated disorder.

Routine breast screening including mammography and breast self-examination (BSE) has been found to be an effective tools for diagnosis of early stage cancers (Feldman, Carter, Nicastri, & Hosat, 1981; Foster & Costanza, 1984; Greenwald, Nasca, Lawrence, Horton, McGarrah, Gabriele & Carlton, 1978; Huguley, Brown, Greenberg & Clark, 1988). Only four out of the seven women, however, had routine mammograms. Three of the women stated that they had delayed their test because of busy life schedules and changes of residence. Only one of the women practised breast self examination regularly and one other said she tried on an irregular basis. This finding is compatible with Lu's study (1995) of 742 Chinese university students in the United States in which 15% of women reported practising BSE monthly while half of the participants said that they never practised BSE. All could articulate the benefits and expressed comfort with the idea, but perceived a lack of competence in the process. Only one third of the women recognized the seriousness of breast cancer. Lauver and Angerame (1988) found that perceived competence at BSE positively correlated with frequency of BSE, and the women's reports in this study support their finding.

The cancer diagnosis was confirmed by biopsy in nine of the participants. It was done by either needle aspiration or incisional biopsy. One participant had a bone marrow biopsy. All but one participant have Chinese family physicians. All of the participants had family physician involvement at the beginning of the diagnosis, either as principal investigator for the health concern or as the physician who first revealed the cancer diagnosis. All of the participants were referred to a specialist and all were referred to the cancer clinic at some point of their illness.

It is a common practice that Chinese immigrants seek family physicians who are of the same ethnic origin, especially the immigrants who lack English language skills. Others may choose a Chinese family physician because they feel that they will be understood better. The family physician as the initial contact with a cancer diagnosis is common in Canada. Current health care practice in Canada is for a family physician to make referrals to specialist physicians as warranted. None of the participants reported difficulty in accessing appropriate care.

Presenting the Treatment Options

When asked during the interviews how treatment options were presented, the participants described different experiences. Some treatment options were presented without any discussion of choice. JEAN's experience was typical of that of most participants:

> After the biopsy and after the cancer was confirmed, he said that I needed to have surgery to have part of the breast removed....he said that I had a bit of cancer, and I would have to have surgery. He then drew some lines and told me how he was going to remove the tissues. He explained to both me and my husband.

When she was assessed at the cancer clinic:

> He (the doctor) said that he received the information from the surgeon. He said in my case, he planned to deliver twenty-five radiation treatments. After the radiation I would need to take the medication for five years. And that was it. He said that the medication was to stop the hormone from reaching my breast. He said that I am 99% clear of cancer. There was a 1% chance that the cancer cells may escape, and where they escape to we don't know. He said that breast cancer most commonly transfers to lung, liver, heart and bone.

JEAN further stated:

> I never asked if there were other choices..... my husband did want a second opinion at the beginning and he phoned the cancer clinic and talked to someone and was told that it was not necessary.

While some participants were able to ask questions when their treatment options were presented, others were not given the opportunity. JOHN's description highlights the problems caused by language barriers:

> He said that I had cancer and needed surgery and I didn't pay any attention...I never asked any questions. I don't know how to ask...I don't know English.

According to the literature, when confronted with a diagnosis of cancer people desire specific information about their disease and treatments (Cassileth, Zupkis, Sutton-Smith & March, 1980; Chesser & Anderson, 1975; Greenberg, Jewett, Gluck, Champion, Leikin, Altieri & Lipnick, 1984; Herr, Kornblith & Ofman, 1993; Lidz, Meisel & Munetz, 1985). Inability to ask questions impedes understanding of the disease and thus the ability to manage treatment. The difficulty with language affected participants' abilities to ask questions.

Other participants had their treatment options presented as choices. Having an opportunity to decide on one's treatment may not be what the patient wants. TINA recalled:

> He said that I could choose to have just the lump removed or to have the whole breast removed. He said that he would need to remove some lymph nodes. He said that the lymph nodes needed to be examined. He asked me to choose. Because I don't really know about medicine, I asked the doctor to choose for me. He asked me my age and I told him that it is 60's, so he suggested having the entire breast removed.

Some participants were given choices at one stage of the treatment and not at the others. JANET's surgical procedure was not presented as a choice. Her radiation treatment was. JANET said:

> The doctor (at the cancer clinic) told me that prior to his seeing me, there was a team of doctors (pathologist and radiologist) who sat together and discussed my situation. He came to speak with me about the discussion. He said that I didn't need to have radiotherapy. He said that my lump was smaller than two centimetres. He said that the radiotherapy would have some side effects...He said that since the lump was confined to the milk duct, he didn't think it would spread. He said that if I insisted on radiotherapy he would do it.

When SUSAN was considering the type of surgery, her prime concern was to ensure that the cancer was removed totally. She discussed her concerns with her doctor:

> We asked the doctor which one would be a better option, removing the whole breast or just part of it. We asked him about two to three times. He kept saying it was not necessary to remove the whole breast. He said that even if he removed the whole breast, the possibility of recurrence would be no different than just having part of it removed. He said the recurrence rate is no different one way or the other...He said if I insisted he would do it.

LOUISE considered the radiation side effects when she chose to have the mastectomies:

> He told me that option one was to remove the lump and then radiation, and option two was to remove both breasts to prevent problems later. So I chose to have both breasts removed. ...I thought it would be

> troublesome to go every day for treatment. And I was not sure of the side effects. He also said that my lungs and rib bones would be affected as well. I preferred to have both breasts removed.

Louise chose surgical treatment. Her rationale for choice of surgical intervention was consistent with what Ward, Heidrich and Wolberg (1989) found in a study of women's choices of breast conservative surgery versus mastectomy surgery. Frequent considerations were fear of recurrence, avoiding a second surgery, physician's preferences, fear of dying from cancer, side effects of radiotherapy, and other people's positive experiences.

Sometimes treatment options were presented to the family. PAUL described:

> According to my family, I was in a coma for ten days. My family told me later what the doctor said. When I was awake the doctor explained to me what had happened.

Presenting treatment options to patients is not always feasible due to the seriousness of the patients' condition, as in PAUL's situation. Therefore family members have to be informed and be involved. If PAUL had been able to make the treatment decision, his family's involvement would likely have been different.

Decision-making Preferences

When asked about their decision-making preferences with regard to treatment options, participants responded in one of three ways. Listening to the doctor, making their own decision, and the role of family members were all considerations. Each of these themes will be discussed more fully. This discussion will be followed by a description of preferences expressed using the card sort designed by Degner and Sloan (1992).

With regard to listening to the doctor, TINA recalled:

> I think in the area of cancer treatment, we need to listen to the doctor. The doctor knows. Some people said that we shouldn't trust the doctor totally, but it is still better than guessing myself. I believe that we should trust the doctor. Even though sometimes doctors may overlook things too, but there is nothing we can do.

LISA shared a slightly different view. She was overwhelmed by the diagnosis of cancer. To defer the treatment decision to the doctor helped to alleviate her anxiety:

> I followed the doctor's advice.... I was so disturbed over the diagnosis. I didn't know what to think. My doctor is like my life saver. If I followed him then I would be safe. Whatever he recommended would be right. If I chose an option, I would wonder if it was the right decision. I don't have the knowledge. Different treatments will have different outcomes. I think it is best that the doctor decide for me the best option.

Trust in the doctor was very important to these participants. Identifying the doctor as an expert in the field inspired trust. There was faith in the doctor's potential to save them and concern regarding the participant's potential to make a mistake because of lack of knowledge. In addition, confidence portrayed in the doctor's mannerisms increased trust as mentioned by the participants.

While some participants preferred to have the doctor choose the right treatment options, others wanted to choose for themselves. As LOUISE states:

> I decided right away on my own. I felt it was my health. I have the right to choose my own treatment. I have a relative who is in her 60s and she had pain in her breast and she had surgery. Its has been over

> ten years now and she is fine. He said that if I only had the lump removed, then I must have radiation. I thought it would be troublesome to go every day for treatment. And I was not sure of the side effects.

JANET responded with:

> I was quite sure about it. I was given a choice and I decided no radiotherapy. The doctor said that I didn't need it and since there is no guarantee that it won't metastasize elsewhere with either decision, I don't think it is worthwhile to go through radiotherapy. Since I had a choice I chose not to have the treatment. My family doctor said once I made the decision I shouldn't feel regretful later. No matter how it turns out. I said I wouldn't. I am not like that. Once I decide on something I stick with it.

Matteson and Hawkins (1990) said that decision-making in health care implies a deliberate mental activity and a choice between two or more options. The final decision occurs after consideration of all variations in the options, and is followed by a commitment to execute that choice. Once a decision is reached, the feeling of uncertainty is overcome, and the mental debate is replaced with the actions needed to execute the decision. Here we have two persons who made deliberate efforts to think through the options presented and made choices based on the following rationales. Someone LOUISE knew had surgery and did well so she was favourably inclined towards surgery as a choice. The trouble of going for radiotherapy every day was perceived as a disadvantage of that option. The belief that one is responsible for one's own body guided JANET's decision, as did considerations of possible side effects and questions about the efficacy of the treatments. In the literature, it is said that people typically consider treatment efficacy, side effects, and their ability to manage these treatments and side effects before choosing treatment options (Herr, Kornblith, & Ofman, 1993; Ward, Heidrich, & Wolberg, 1989). Haug and Lavin (1980), in their study of factors that influence people's treatment decision-making, found that individuals' beliefs affect their willingness to be involved in treatment decisions. JANET believes that her body is her own responsibility and that affects how she prefers to choose the treatment options. Personal beliefs account for some of the variations in people's desire for decisional control as is evident in this study.

Most participants felt treatment decision-making should be negotiated between themselves and their physician and that family could best participate in supportive roles. When asked if they would involve their families in treatment decisions, JANET, LISA and LOUISE shared similar views:

> I believe for this kind of thing I have to make the decision. It is not useful to ask my family. It is up to me. (LISA)

JOAN and TINA felt that their family would not have the knowledge to be involved and therefore they have to decide themselves:

> My husband doesn't have any opinion. He doesn't have any medical knowledge. (TINA)

SUSAN, JEAN and PETER felt having family with whom to discuss treatment options is beneficial:

> I discussed with my daughter whether he should remove the whole breast. I discussed with her whether removing part of the tissue would be sufficient to clear the cancer. My daughter and I both thought this way. (SUSAN)

Existing literature suggested that the family model of decision-making is common among Chinese patients (Muller & Desmond, 1992). My study revealed conflicting findings. The general belief that Chinese people, when they become ill, choose to assume a sick role, allowing the family to make the decisions and to provide care, is not supported. Possible explanations include: (1) by explaining options to patients and soliciting their opinions, physicians encouraged patients' involvement; (2) people are more informed nowadays and are more willing and able to participate in the decision-making process; and, (3) Chinese people have changed their views and now desire greater autonomy in health care. It is evident that the participants in this study valued family involvement but only in a supportive role. This is congruent with the literature that suggests that Chinese people consider family as the most important source of social support (Lindsey, Dodd & Chen, 1985; Lu & Chang, 1997; Ngan, Tang & Lau, 1994).

The card sort technique was first introduced by Degner and Russell (1988) and has been used by many researchers since then. Five decision-making possibilities are presented. The five scenarios are:

A. I prefer to make the final selection about which treatment I will receive.
B. I prefer to make the final selection of my treatment after seriously considering my doctor's opinion.
C. I prefer that my doctor and I share responsibility for deciding which treatment is best for me.
D. I prefer that my doctor makes the final decision about which treatment will be used, but seriously considers my opinion.
E. I prefer to leave all decisions regarding my treatment to my doctor.

When the participants were asked to choose one scenario among the five and asked which one best represented their way of thinking, some of them gave a response quite readily and others answered with some hesitancy. The majority said that they would choose option E which is to leave all decisions regarding treatment to the doctor. JEAN said:

> The last one (E) most resembles my thinking, that is I prefer the doctor to make the treatment decision for me. Because I don't understand medicine, he is the expert and therefore he should be the one to make

> the decision.

TINA described her choice as:

> I choose the one that says let the doctor decide treatment options for me (E). But it is not obeying blindly. I would ask him to explain things to me and then analyze it myself and then decide quickly. And if I can't decide, then I would ask the doctor to help me.

PETER said:

> From the start of my illness to now, I have followed the physician's recommendation. Because I feel that the doctor would know what to do. So I followed the doctor's suggestions.

While PETER chose (E), he felt that he could trust some doctors totally while with others, he had to state his opinion and not trust them blindly.

LISA's answer indicates an awareness of the complexity of decision-making:

> I don't think one would have one single answer. Look at this one (pointing to E), the doctor will decide which treatment option, but he needs to explain to me what he would do. Choices would be decided by the doctor. But I would like to be informed and given an explanation of what he would do.

JOHN said:

> The last one (E) says "I prefer to leave all decisions regarding my treatment to my doctor....". We trust the doctor to make the right

> decision for us....We don't have the knowledge. The doctor knows what to do.

PAUL indicated (D) and then said:

> I like to discuss with the doctor to find the reasons before I trust him...If the reason is not good enough then I would reconsider.

SUSAN also chose (D), saying, "I like the doctor to choose for me, but first to listen to what I have to say." Janet chose (B) and explained her choice, "I think the "B" scenario most resembles my thinking. I like to listen to what the doctor says and then make the decision on my own." LOUISE also chose (B) and this is how she explained it: "I like to make the decision myself but first I considered the doctor's opinion."

It is evident that the participants found it difficult to choose among the cards and find one that adequately described their preference. They implied that there was no single or easy answer and felt it necessary to attach qualifying statements. Such statements included "but it is not obeying blindly..." or "depends on whether I trust that doctor" or "...but he needs to explain to me what he would do" or "I like to discuss with the doctor to find the reason before I trust him". These patients' qualifying statements raise questions about the validity of the quantitative research using the cards. How accurately are people's true preferences captured? How well are their feelings towards decision-making identified?

Two out of the ten participants chose option (D), six chose option (E), and 2 chose option (B). According to Degner and Sloan (1992), people who are passive decision makers would choose options (D) or (E). People who are active decision makers choose options (A) or (B). In this group, therefore, eight participants preferred relatively passive decision-making roles and two preferred relatively active decision-making roles.

The findings are similar to other research where results indicate that the majority of patients prefer a passive role in cancer treatment decision-making (Beaver, Lukar, Owens, Leinster & Degner, 1996; Davison, Degner & Morgan, 1995; Degner & Sloan, 1992). What was surprising was that there was no suggestion that none of the cards represented anyone's true preference. Prior to the study, there was an assumption that this population may prefer family involvement in decision-making, including the family rather than the patient or the physician making the decision. This did not happen.

The Chinese-Canadian subjects made choices consistent with the research in the mainstream Canadian population. The card sort technique findings are consistent with what appeared in the interviews. It is important to note that two of the participants chose option (B). In the interviews, prior to participating in the card sort, both of these participants indicated they preferred to choose their own treatments. The participants who chose the active decision-making role are both women. They have adequate English language skills, good incomes, and are younger and more educated than other participants. According to the literature, gender, age, education level, and socioeconomic status affect willingness to participate in treatment decision-making. As there is no agreement on how these factors influence decision-making, other factors should be considered. Both women have independent lifestyles. JANET lives in Canada with her two sons and her husband is in Hong Kong, so she has developed an independent style of dealing with problems at hand. Cancer diagnosis was perceived as just another such event. LOUISE related her past experience as full of hardship. From a very young age she had to take care of her parents and consequently developed an independent style as well. The rest of the participants chose to have the physician make decisions for them. Even though they preferred their physician to make the treatment decision for them, they still wanted to be informed of their diagnosis and the treatments. This finding is consistent with the literature which has focused on mainstream culture (Beaver et al., 1996; Hack, Degner & Dyck, 1994).

Making cancer treatment decisions is a complex task that requires cognitive ability. Patients' emotions may influence their ability to think clearly. Factors that affect decision-making include personality traits and previous life experiences.

According to Matteson and Hawkins (1990), a person's ability to make health care decisions lies in the person and the environment. Personal factors include personality type (dependent or independent, passive or active), beliefs in the sick role model versus a belief of consumerism, cognitive ability and problem solving skill (ability to follow the mental map of choosing and executing an action), and stage of illness.

Environmental factors are situations that surround the person in times of decision-making. Examples include one's relationship with the health care professional (like trust and respect) and the health care environment (which includes organizational culture in resource allocation and the health care professional's belief in fostering the patient's decision-making capacity). Resources include time and the availability of interpretor services for people who have language barriers. Time is an important element. Patients need time to think things through. Health care professionals' beliefs in patients as consumers with rights to determine their own health care also influence the health care environment. Furthermore, health care professionals' respect for patients' values and beliefs affect their willingness to listen to what patients say. For this reason, aspects of the environment of the participants in this study will be discussed later in this chapter.

Living with the Treatment

Once the treatment choice was determined, the participants underwent the intervention. The following paragraphs describe treatment side effects, ways to remedy these side effects, awareness of the side effects, and recovery from the treatment and the side effects as experienced by the research participants. PETER and JOAN are two of the participants whose treatment experiences deserve special attention as they suffered extensive complications from cancer treatment.

In describing treatment side effects, different experiences were voiced by participants. Some of the participants had minor side effects such as skin irritation from the radiation and minor pain from surgery. Treatment side effects are determined by the type of treatment and the severity of the disease. PETER described the detriments of his radiation treatment:

> It was extremely painful. I took medication and received injections...I was really sick. I had no energy left. I was not aware of what is going on. I couldn't tell day from night. I couldn't eat. I couldn't think... They gave me Morphine and later they gave me pills. These are all analgesics. Then I got constipated from it. This was troublesome for me.

JOAN experienced the most complications after her mastectomy surgery. She had a lot of incisional pain. She was distressed:

> I don't know whether the stress caused the pain or the pain caused the stress. He (the doctor) said I was emotional. He said I was emotionally unstable. My lack of sleep and stomach pain and all kinds of symptoms. May be it is the stress that caused the pain. My psychologist thinks so.

JOAN was given medication for pain and to control her mood with no effect. She sought help from a physiotherapist and had some good relief from the treatment. At the time of the first interview, pain was mentioned at length. Her feelings of dissatisfaction were readily identifiable. She took other steps such as seeking out massage therapy and also has seen a herbalist. During the second interview she appeared more comfortable. She has found ways to manage her pain but it was still very much on her mind. She felt that her experience is not shared by others. She has thought about her pain and tried to make sense out of it. JOAN described:

> I keep thinking, three, six, nine months it would be better. I look well and they find it hard to believe I have pain. When I complain they don't know what to do with me. Even the lady from Reach to Recovery doesn't call me anymore. I told them about my pain and they have never experienced it. I am debating whether to go for acupuncture. It

> seems that all decisions I have made in the past few months are bad ones.

One gets the feeling that JOAN may regret the decision to have a mastectomy. When asked about the rationale she used to decide on the treatment, however, she felt that it was a matter of survival. She was not regretful of the surgical decision she has made. She was, however, resentful of the lack of support when she experienced the complications and that she felt inadequately prepared to deal with these complications. Even though the majority of participants were suffering minimal side effects, there were others who were not managing well. JOAN illustrated the helplessness that health care professionals felt when this happened. She said, " they don't know what to do with me".

Strategies use to remedy treatment side effects were described by the participants. For example, PETER said:

> With the radiation, my teeth were affected. They removed all of my teeth. I could only take liquid. I lost all of my teeth. My mouth hurt from the radiation. I took a lot of medication. I needed to have more nutrition. I lost a lot of weight and I couldn't eat. I needed some time to recover.... I was getting tube fed...they taught me to do my own tube feeding..I learned to do it and I did it four times a day.....later, the tube got infected. I went to see the doctor and the tube got removed. There was so much pain. Then gradually everything began to improve, my mouth, my appetite. I brought meat home but I couldn't chew so I bought a blender to grind up the meat. I eat congee (rice porridge) and rice. I cook the rice and make it softer. The meat and vegetables I blended it up or I just drank the broth.

The reactions from cancer treatment are variable among the participants. Most of them had very few side effects and they managed these side effects on their own.

Pain was described by several participants. One of the things that is feared about cancer is pain. One participant described her experience of using herbal medicine and massage therapy to deal with the pain. Acupuncture was suggested to her and she was considering it.

Most of the participants were aware of the treatment side effects to which they were vulnerable, but some were not adequately prepared for the side effects when they occurred:

> Since I have not experienced it before, I didn't realized that there is no saliva. I know it was serious. I didn't know that the secretion of saliva would be affected (by the radiation) as well...and my nose is always a bit plugged. He (the surgeon) was going to do a skin graft, but instead he pulled this skin flap over and so this is crooked and my nose is always a bit plugged. So then I tended to breathe with my mouth. So my mouth is dry. If I don't talk, my mouth won't get so dry. (PETER)

> He cut so much. It was painful. I don't know why he cut so much. (JOAN)

It appeared that some participants were not aware of side effects such as dry mouth, nausea and pain. The lack of understanding of side effects created hardships for them.

Most participants managed their treatment side effects well, contrary to Dodd's findings (1984). Dodd, in her study of 30 cancer patients who received radiation therapy, found patients reported side effects such as skin changes, difficulty swallowing, fatigue, diarrhoea and nausea. These patients reported experiencing three or more side effects from radiation and initiated few self-care activities to remedy these side effects. They said that they had to obtain information about ways to manage these side effects from mostly informal sources, such as media and friends. She also found that nurses offered little informational support, while some was offered by physicians. The participants in my study seemed to demonstrate a good understanding of side effects and were involved in self care activities to manage these side effects. They often described wellness as being able to eat or sleep or in terms of weight gain. Being pain-free was another way they described their wellness. Two participants had side effects that were difficult to manage.

JOAN had the most difficult time after her mastectomy. She had a rough course of recovery with much incisional pain that was not relieved by analgesics. The surgical area was sensitive. Her pain experience led her to seek help from a psychologist and a physiotherapist. Most disturbing is that she felt no one listened to or believed her complaints. After the second interview, she started to see a herbalist and made attempts to see a massage therapist. Her pain remained bothersome at that time. PETER, due to the extensiveness of the radiation, had more side effects and a lengthy recovery. Use of TCM in the management of side effects and promotion of health is discussed later in this chapter.

Interaction with the Health Care System

While the Chinese-Canadian cancer patients in this study shared decision-making preferences which are similar to those of the general Canadian population, their desire for disease information had some unique characteristics. Cultural and linguistic differences can affect access to relevant knowledge.

The Need for Information

The role of information in relation to cancer treatment decision-making has been studied. In the following paragraphs, the information needs of participants in this study are explored. The discussion will focus on information seeking behaviour, types of information given, perceived understanding of the disease, perceived benefit of the information, and additional information sought.

Participants were able to get information from a variety of sources. Written information was given by health care professionals in the form of pamphlets and books. Most participants thought that information translated into Chinese would have significant benefit for people who cannot read English. Even though there seemed to be need for translated information, three out of ten participants had limited Chinese reading skill. As they also lacked literacy in English, their acquisition of information was limited. LOUISE used a medical dictionary to try to understand the medical terminology so as to understand what she read and to understand what the doctor said. Some participants obtained general cancer information from the Chinese newspaper. Other participants borrowed books in English from the library at the cancer clinic.

Other information sources were Chinese radio and television. Janet subscribed to Medical Letters to keep informed of the newest medical news. Her English reading skill and her motivation allowed understanding of this source of knowledge. Video tapes were found to be useful as the person could play them many times in an effort to understand the content. JANET was able to utilize the community pharmacy outlet as an information resource. She also borrowed tapes on health matters from the Safeway Pharmacy, including tapes on cancer and its treatment. Verbal information was given on a regular basis and most participants found that they could understand the information when given slowly or through an interpreter. Some participants found verbal information more useful than reading. As LISA described:

> Reading is not as good. When he (the doctor) explains to me and I don't understand, I could ask the question right away. (Reading is more difficult) as I might not retain the information.

She said that when a person's mood is low it is harder to remember information. Verbal information allowed interaction. Questioning led to immediate clarification which enhanced memory. Some participants obtained information from lay persons such as relatives and friends. TINA cautioned that information should be obtained from credible sources; from people who are trustworthy. LOUISE has relatives and friends who are nurses and doctors and she obtained information from them on breast cancer. PETER, JOHN and PAUL did not attempt to obtain any kind of written information as they believed that their inadequacy in English would be a barrier to understanding.

Most participants thought that they were given sufficient information on the physical aspects of the disease such as severity of the disease, the treatment options, and the treatment side effects. Severity of the disease was explained as cancer stages and numbers of nodes involved. Treatment benefits were described in terms of reduction in percentage of recurrence and metastasis. LISA stressed the importance of timing of the information:

> I was so depressed. I never thought to find information. I only thought about my family. Now and when things were settling down, I started to pay attention to the information given on television or in the newspaper about cancer.

These participants came from a variety of educational backgrounds. Their formal education was from their native countries and years of education did not correspond with English language proficiency. Most participants had either a family member or a formal interpreter to assist with understanding of the information presented. Most participants verbalized undertanding of what they were told. JOHN and PAUL thought that they did not know enough about their illness and its treatment. Both of them had family members as interpreters. It is not clear whether all information given to the family was provided to the patients. JOHN perceived that the family might not have told him everything and wished he knew more. PAUL was content with what little he knew. LOUISE, on the other hand, really wanted to understand what she read.

All participants felt that they needed to know about their disease and its treatment. JANET said it very well:

> Information gathering is important. Getting information will help a person prepare for a situation.

Information gathering is a way to cope with the cancer diagnosis and was seen as useful and necessary. LISA was ambivalent about information:

> I never thought to find information. I think this was a way to avoid the issue. I didn't want to know too much.

Information avoidance is another way to deal with the cancer diagnosis. JOAN felt that information that reads like a medical dictionary was not useful. She thought information of that sort would increase her anxiety level:

> The cancer books I read, they described symptoms and every symptom they described, I seemed to have it. It made me worry.

She would have preferred to have information that discussed prevention of cancer and ways of healthy living. LOUISE thought the timing of the information was important. She felt that information regarding types of treatment should be available before any treatment was initiated, even before the surgical resection:

> Before surgery, I was very busy. I didn't know there were books that I could borrow....If I knew, I would have read something before any treatment.

All participants perceived the value of cancer information. Their information needs, however, were not uniform. As information is critical to a person's understanding of the disease and to deciding treatment options, the timing of the information deserves consideration. The elements to consider include when to give the information and how much information to give. There should be an ongoing evaluation of change in information needs. Consideration given to individual patient's special needs is important. For example, JOAN expressed interest in information about cancer prevention and ways to promote health and gave less value to information that described the biophysiology of cancer. LISA did not want too much information at the beginning as she found the information itself anxiety provoking. LOUISE would have liked to read more about the treatment options even before her surgery.

Some participants desired more information on foods and nutrition. JEAN was told by her relative not to eat "She Kep Ko" (a substance with mucousy consistency) or foods that contain hormones and she wanted to know what foods contain hormones. Others desired information on TCM and herbs. The most frequently asked questions were whether they could continue to eat certain types of herbs and whether it would be harmful to combine both Western and Traditional Chinese Medicine. Only one participant took herbs to cure cancer. Four participants took "Fa Kee Sum", which is a mild herb used to increase vitality. It is used as a tonic. PAUL said that both Chinese and Western medicine were used during his hospitalization experience in China.

PETER was somewhat concerned about whether he should seek Chinese medicine for treatment and at the same time articulated his perceptions of the limits of Chinese medicine. JANET thought of going back to Hong Kong for treatment and described the problem of accessing TCM here in Canada. She did not know which Chinese herbalist or practitioner she could trust because of the lack of accreditation and certification of Chinese medicine here. JOAN was actively seeking TCM for her surgical pain.

Some particpants wanted to know how long they had to live, a common question asked when people are confronted with a cancer diagnosis. Some verbalized that their physician had limits and really did not know all of the answers.

Lack of language skill is a significant barrier to accessing information (Anderson, 1986; MacKinnon, Gien, & Durst, 1996; Tabora & Flaskerud, 1997). The participants in this study were of different educational backgrounds and had varying degrees of language proficiency. They expressed difficulty in five areas. Having to have someone else interpret led to uncertainty whether all information from the doctor was conveyed to them. The inconvenience of involving a family member, expending their energy and time, was mentioned. Lack of ability to ask questions if information was not clear was a barrier to understanding. Lack of privacy may be a factor as some questions were not asked due to embarrassment. Finally, when a relative/family member acts as an interpreter, the language skill of the person who interprets may be in question. JOHN described the difficulty:

> He (the doctor) told my family that I needed surgery but he didn't tell them too much. He just said that I have cancer and require surgery...They (my family) didn't (tell me). Only after the surgery that they told me...She was afraid that I would worry. But after the surgery, I didn't know about what really happened until my family told me. My wife said that the doctor told her that I had cancer.

JOHN did not know whether follow up with the surgeon was required. While JOHN and his family were waiting for the call from the surgeon's office for a follow up appointment, the surgeon's understanding was that he would be followed by the family physician. Such miscommunication was due largely to the lack of language skill. JOHN stated:

> My surgeon never called us about an appointment. He didn't check me yet since the surgery. I would like to ask him what he removed and what are the chances of it recurring. I would like to know something about my cancer. I would like to know what I should do, what to avoid. I would like to know how long I will live.

Another example of lack of understanding related to language skill is demonstrated by PAUL's limited knowledge of the bone marrow aspiration procedure:

> I heard that it was really bad to have a bone marrow aspiration done. Whoever has it done always ends up paralysed. There are many

children end up paralysed because of it.

Such lack of understanding can provoke unnecessary stress. Among the ten participants in this study, the difficulty in getting information from health care professionals seemed to be more pronounced with the three men (PETER, JOHN and PAUL) who came from China and the two elderly women (TINA and SUSAN) who came from Hong Kong. The remaining five participants experienced fewer difficulties. These findings demonstrate the diversity of backgrounds from which Chinese immigrants come. This diversity results in variable difficulties with the Canadian health care system.

Some participants sought information from informal sources. SUSAN obtained information written in Chinese from newspapers and from friends. TINA, on the other hand, was reluctant to seek out information from informal sources such as friends. PETER gained verbal information from formal sources and through interpreters. JOHN and PAUL had relatives as interpreters and they experienced the most difficulty in accessing information as they felt that not all information from the physicians was conveyed to them.

The remaining five participants were able to obtain information actively on their own. JEAN has a supportive husband who borrowed books from the cancer clinic library, read them and then explained what they contained to her. JANET, LOUISE and JOAN actively sought information on their own which led to better understanding of their disease. LISA sought verbal but not written information, as she found she could not retain written information.

The participants experienced variable ability in obtaining information. Language proficiency and family support are influencing factors. In terms of accessing services, existing literature describes Chinese immigrants' hardship (Anderson, 1986; Chan-Marples, 1993; MacKinnon, Gien & Durst, 1996). Lack of awareness of available services is common among Chinese immigrants. Some of the participants in this study were not aware of the Canadian Cancer Society and what services it could provide. PAUL was unaware that he would have to pay around eight hundred dollars per month for a palliative bed in a long term care facility while recovering from his cancer. The cost itself posed enough difficulty that he decided to go home. Some Chinese Canadians are only beginning to learn about the health care environment where hospital stays are minimized and home care service is the major provider. JOHN and PAUL were unaware of the transportation service to the cancer clinic and relied on family for transportation and interpretation services. JOHN refused to participate in a study at the cancer clinic as he did not want to impose on his relatives for the daily transportation required as part of his participation. There is a belief in Edmonton that Chinese persons are reluctant to participate as research subjects. It is possible that inconvenience and lack of awareness of available supports is a greater obstacle than an inherent Chinese predisposition to avoid such activities.

There was considerable variability among the participants in their awareness and utilization of the services offered by the cancer clinic. Transportation services to and from the cancer clinic for radiation treatment and psychology services were used by one of the participants. The patient library was well utilized by several participants. Some of the women in this study were well aware of the "Reach To Recovery" organization as they were visited in the hospital, were given information on arm exercises, received follow-up calls from the organization, and received emotional support and positive messages. Most participants were aware of and had contacts with the volunteer services at the cancer clinic for supports such as greeting, orientation to the clinic, transportation, interpretation, etc.

Other service agencies such as home care were utilized by several participants. Both PAUL and PETER were able to utilize Alberta Assistance for Daily Living (AADL) services to obtain a walker and bathroom equipment with the assistance of a home care coordinator. PETER obtained help from a home support worker for personal care when he first returned home from the cancer clinic and was able to maintain tube feeding at home with home care assistance. Several participants utilized home care nursing services for post-operative wound management. PAUL did not enjoy his experience at the long term care facility as the food that was served did not suit him.

Communication and Interpretation

Communication is the essence of human understanding and relationship. A commonality among the participants was the utilization of informal interpreters, such as family and relatives or people who worked in the institute. Formal interpreters were used as well. PETER described the change:

> I heard that before there were special people to interpret, but later there was a budget cut and this service no longer exists. Now they have a list of the staff who can speak different languages and when they have the need they ask the staff to assist.

PETER, JOHN and PAUL utilized this service on occasions. All participants except JANET, JOAN and LOUISE utilized family members such as husbands, sons, daughters, and other relatives for interpretation. JOHN described the hardship of not being able to speak directly to the doctors:

> He (son-in-law) can interpret for me. But he doesn't know the medical terminology for the internal organs. He can get by with day to day English.

Therefore, it was common that the family had problems relating information back to the patients and considerable information may have been lost. An additional problem occurs because of the protectiveness of family members. JOHN described this situation:

> He (the doctor) told my relatives. My relatives didn't tell me. The doctor spoke English. He didn't tell me anything. My wife didn't tell me either. My wife was afraid to tell me about cancer. She didn't tell me because she thought I would worry too much.

It was common for family members to disclose partial or no information to the patient. Sometimes family members would wait for a later date to tell the patients. That was the case with JOHN. He found out that he had cancer through his family after the surgery had been performed. Using family members as interpreters can pose difficulties for patients who want to know about their health condition. The common belief that Chinese people desire their family rather than the patient to be told of life threatening illness is not supported in this study. As JOHN said:

> I like to know what kind of cancer it is, the chances of spread in the future. I have a few questions that I would like answers for. I just couldn't ask them.

Some other participants used family members as interpreters and were satisfied. TINA and SUSAN had their children as interpreters while JEAN and LISA brought their husbands.

Verbal communication is only one way to communicate. Some participants found ways to get around the language deficit and to express their needs. PAUL said:

> I used signs to indicate what I wanted...I told them by pointing to the bathroom. The bathroom was in the same room.

SUSAN was able to make the best out of a seemingly difficult situation. She said:

> The nurses asked me to teach them Chinese...They asked me how to pronounce pain, how to say injection, pain killer and so I taught them.

The learning was often mutual. PETER was able to learn a few words while he was in the hospital. TINA said:

> The ordinary English I could understand. Some I try to guess by

observing their actions.

The ability to communicate is essential in a patient-doctor relationship. Nine out of ten participants in this study have a Chinese doctor as their family physician. Lack of skill in the English language was not a problem in communication with the family physician. Once the participants in this study were referred to a specialist, however, English was needed. JANET described her experience:

> I read books for that reason. I knew what he was talking about. Especially the medical terminology. When he said it, I knew what he meant. The doctor, when he knew my mother tongue was not English, he would not use too many medical terms. Sometimes when he tried to explain things, I would ask him if he meant that and he would say yes.

JANET had good English skills compared with the others but managing every day English is different than understanding medical information. With some sensitivity from the doctors, patients who have limited language skills may be able to increase their understanding about their disease.

Fostering Communication

Fostering understanding requires techniques such as slowing down speech, using simple words, avoiding medical terminology, and using gestures and facial expressions. Even though participants exhibited varying degrees of a language deficit, they were able to convey their messages to the health care providers using simple language, through an interpreter, or simply by sign language and gestures. It is evident from the data that the majority of the participants found ways to communicate with the health care providers. The hardships seemed greater in people who came from China. JOHN said it well:

> Here in Canada, if you can't speak, you are dumb; can't read, you are

> blind; can't drive, you are physically disabled; can't hear (and understand), you are deaf.

Use of Traditional Chinese Medicine

The feeling towards and the utilization of Chinese medicine were quite diverse among the participants. Some participants did not believe in Chinese medicine and had not practised it even in their home country. PETER clearly expressed his cynicism about TCM:

> Sometimes people claimed that it worked but were lying. Some are saying nonsense and making false claims, guessing at best...I don't really believe it.

Others wanted to find a good Chinese medical practitioner but did know how to begin. JANET expressed concern:

> It is hard to find out who has the proper training. Anybody can claim to know Chinese medicine, especially the herbalist. Chinese medicine has existed for so many thousand years and it must be sound. Chinese medical concepts are good. The problem is it lacks proper training and certification process (in Canada) to ensure quality practice.

Her concern is shared by LISA as well:

> If I am in Hong Kong I may think that way (to see a Chinese doctor). But here there are few Chinese doctors. Not all the herbs are available here. I don't know which Chinese doctor to trust. And there is no health care money to support seeing a Chinese doctor.

The concern of finding a Chinese doctor who is qualified and certified to practice

TCM is valid. Funding to cover people who want to seek out alternative medicine is unavailable and also deserves attention. PAUL made an interesting comparison between Western and Chinese medicine:

> Western medicine is not good for the stomach...my stomach ulcer is caused by too much Western medicine. I never had an ulcer before. It gave me an ulcer.
>
> In China, both Western and Chinese medicine are used. We can take Chinese or Western medicine. In the hospital, they use both. They used one dose of Chinese medicine and three doses of Western medicine...They are given at different times.

This comment reinforces the comment by Forgac (1994) that Western Medicine is used for treatment of many conditions while TCM is used to ameliorate side effects and promote healing.

JOHN supported PAUL's concern about Western medicine:

> A little pain I can tolerate and I won't take the pain medication. Pain medication is harmful to one's Qi.

JOHN said he did not know if Chinese medicine could treat cancer:

> Surgery is the way to treat it. Chinese people use herbs. Some of them are good for increasing your strength.

Use of herbal medicine varied among the participants. Some routinely utilized some sort of herbal remedy to promote well-being, stimulate appetite, clear bodily toxins, etc. Most of them had learned its use from friends and family. SUSAN found information on the use of a certain mushroom to clear cancer from the Chinese newspaper where a Chinese medical doctor discussed the benefit of "Hau Tau Ku" (type of mushroom) in curing cancer. She also saw a Chinese doctor for a herbal formula and used it quite regularly. JOAN had done the same. No one had tried acupuncture, although it was recommended to JOAN by her doctor to deal with her pain.

Self medication was practised among the participants as well. TINA recalled her first cancer experience while in Hong Kong. She used dried millipedes and herbs to make soup to drink prior to the radiation treatment. It was intended to get rid of the toxins, but once radiation started she did not take it again. She said that she was advised not to take herbs that would spread the toxin around during radiation. PAUL spoke of his experiences with self-medication in China:

> When I was sick, I would go to see the doctor in the factory. Sometimes I would buy some medicine and take it myself...It came in packages. All I had to do was boil it.

SUSAN also self-medicated:

> When people tell me to make soup with the anticancer foods, I do. This friend who introduced "Hau Tau Ku" advised using this together with "Yee Mai" to make soup. Add chicken or pork bone to it. Now I use it in soup quite often. It could help to clean up the bowel. Some people tell me to have my feet massaged. I do. I had diabetes for a few years and I never took any medication. I massage my feet and now I don't have any problem...I learned in Malaysia. This book has good instruction (pointing to a book in the cupboard).

PAUL, JOHN, TINA and SUSAN used "Fa Kee Sum", a herb that is used as a tonic to increase vital energy.

There is concern about the practice of self medication. Knowledge of TCM is retained by Chinese immigrants in varying degrees. Historically, the concepts of TCM were found in written form and passed down in written and verbal forms. The written information could be understood by Chinese scholars and the elite members of society who could read. Illiteracy rates were high among the Chinese general public. More typically, the Chinese people learned about TCM by word of mouth; passed on by parents or friends. Verbal dissemination of knowledge can be problematic. Over time, the understanding of TCM by the general public may become inaccurate. Lam, Catarivas, Munro, & Lauder (1994), in a study of self medication practice, said that such inaccuracies are common among the Hong Kong Chinese. They learn the use of the medications from their family and friends and their knowledge of the side effects is limited.

Use of foods to promote health was found among the participants, even the participants who did not believe in or utilize Chinese medicine. Participants expressed thoughts about the avoidance and utilization of certain foods. Certain foods were used for "patching" purposes, which is thought to strengthen the Qi. It is believed that surgical procedures drain the Qi and patching is required to replenish the Qi. Meat broth and chicken, especially black chicken, also called black-boned chicken (which is chicken with black-coloured skin and meat), are thought to be good for patching. Tina used snails and turtles for the same purpose. Sometimes herbs were added to the meat broth. Some used "hot" and "cold" foods to restore balance, an example being eating cantaloupe following radiation as radiation is considered "hot" and cantaloupe is "cold". Cantaloupe also increased fluid intake, which was recommended by her nurse, as Tina recalled. Some foods, such as Yee Mai, were consumed to clear the toxins in the body. One participant consumed a certain type of mushroom (Hau Tau Ku) in hope of curing cancer. Four of the participants take Fa Kee Sum to increase vital energy. There was evidence of an integration of Chinese therapeutic diet ideas with western dietary principles. Thus it was common for participants to talk about vitamins and the need for a balanced diet as understood in western nutritional standards. Some food items were avoided. The reason for a food's use or non-use varied. The information was shared among friends and its validity was questionable, but the participants would say that they tried it just in case there was truth in it. LOUISE was told by her doctor to avoid the Chinese mushroom but did not know why. When it was suggested that she inquire about the reason, she said:

> He is so busy. I don't want to bother him. It is so minor. I won't eat this kind of mushroom while I am going through treatments. Gradually, I will eat it again. It is alright to eat a little.

LISA said to avoid shrimp and crab after surgery as these foods could cause infection in the incision and impede wound healing. JEAN was told by her friend not to eat "She Kep Ko" (a substance obtained from a frog found in the northern part of China) and to avoid hormone-containing foods. She did not know which foods contained hormones and wanted information about that. Some participants resorted to Western food and nutritional concepts of balanced food groups. Some thought fruit and vegetables and oatmeal would be good foods. One participant talked about the use of garlic to prevent cancer. Another participant talked about vitamin use.

There was variability in dietary beliefs and lack of understanding of why certain foods should be avoided. This confusion can cause conflict and stress in a person. Joan experienced such a dilemma. When she was told by her friend not to eat chicken, she said: "I don't know what to eat any more".

The connection between food and health is a major part of TCM (Gigante & Zhang, 1996). Good dietary practices are relatively easily attainable and affordable and can be part of a person's everyday life. What better way can a person promote his/her health but to start with sound dietary practice. The concern then, for the participants in this study, is to disseminate this information to the lay Chinese people uniformly and accurately so that the full benefit of the therapeutic use of diet may be realized.

Relationships with Health Professionals

The Chinese-Canadians who had cancer, by and large, were able to obtain information from health care professionals and from other sources. The health care environment in which they reside allowed for this to happen. One of the factors that facilitated this happening was their relationships with the health care professionals they encountered.

Relationships with Health Care Providers

The participants verbalised satisfaction with the care they received during their diagnostic and treatment period. There were many positive comments about the services received. All participants thought that they had received good care:

> The nurses and the doctors are good. They are so friendly....they smile at me..their attitudes are good. He (the doctor) was so friendly. He treated me like a friend. He started by saying something general to relieve my anxiety...It feels good to be around them. Their attitude affects the patients. (JANET)

It seems that understanding of language is not the prerequisite for good care in the minds of these cancer patients. There is little doubt, however, that communication barriers impede understanding and thus have the potential to adversely effect outcomes. Could it be that these Chinese immigrants have few expectations regarding the likelihood of having information needs met?

> The nurse was good. She came to hold my hand. I knew she came to comfort me. I couldn't hear (understand) what she said but I knew she tried to comfort me. Their attitude was good. (TINA)

> Despite the communication barrier, we were treated with respect. Their attitude is good. (JOHN)

A few negative comments, however, were expressed by the participants. JOAN had reservations about the care in the cancer clinic as she did not see the consultant doctor, only the assistant, and she felt abandoned. PETER felt somewhat rejected as he was asked to go home before he felt ready. He learned that it was necessary because of the limited resources in the region. JOHN had a bad experience immediately following surgery as he could not find the bell to call a nurse and his intravenous was running dry. He managed to get out of bed to look for a nurse outside of his room. The overall impression was that respondents felt they had received good care and that the concerns voiced were not related to cultural or linguistic misunderstandings.

Relationship with the Physician

Relationships with physicians were generally good. Elements of trust and confidence were expressed strongly:

> The doctors are trained and they have many years of training, and their source is credible. I have confidence that my doctor knows what to do. I believe in the doctor. (JEAN)

> I believed in the doctor...He is friendly and I had great confidence in him...I believed God had arranged for this doctor to see me and I just left it at that. I believed that God treated me through Doctor M's hand. I believe God has made me well. (SUSAN)

TINA has certain expectations for a good doctor, which include openness with information. She said:

> I prefer for him to tell me everything. So I don't have to be guessing. Doctors have to show patience and listen. If he pays attention to you

> then he is good.

She also realized the doctors have limits. She stated:

> Doctors could make a mistake, but that would be fate if I was to be treated by a doctor who was incompetent.

SUSAN further supported TINA's comments about what a good doctor should be like:

> From the way they smile. I was lying on the operating table and the doctor was on my right......he was so nice, he came and held my hand. I couldn't talk to him. All I could say was " thank you" many times.

The participants' perceptions of a good doctor incorporated factors such as having good communication skills, making kind gestures, patience, openness and honesty.

Others trusted their doctors for other reasons. These reasons included perceptions regarding expertise, reputation, referral from someone they trusted or had known for a long time, or simply by virtue of their position as doctor. All of the respondents expressed positive evaluations of their physicians.

In general, the participants had good relationships with their family doctors and their surgeons. They also felt they were received well at the cancer clinic. Even though most participants trusted their doctor and were able to explain why, others did not share the same feeling. PETER expressed his concerns:

> He didn't spend any time to explain to me, and also he took it too lightly. He is not a careful doctor. He needs to be more careful when treating patients' illness. You can't tell patients that it is nothing and it is not serious...I always thought of him as being a bit too

> careless....He is not serious with his work. I didn't see him once, I saw him many times. Each time he told me a few words and then brushed me off. He kept telling me to relax and to trust him.

JOAN was not completely satisfied with her encounter with her doctor either:

> He is very busy. He doesn't have time to explain things...They (the doctors) were kind of rushed and didn't really answer my questions. I was led to believe that they, the surgeon, the family doctor and the doctors at the (cancer clinic) all work together on my behalf. But that was not the case.

She further explained:

> Because after the surgery my family doctor didn't really talk to me about any follow up. And the surgeon only cared about the incision. Post surgery, the emotion and the pain no one seemed to care about. And there was no follow up by the (cancer clinic) and I am now discharged. So there was no team...I understand the surgeon is very busy and he has no time to go through things with me. But if my family doctor, according to the readings, family doctors are one of the team members, if my family doctor played his role. I found his role was not there. I had to go out of my way to find different resources. His role wasn't there.

JOAN on the other hand, recognized the doctor's limits:

> When someone does not complain that something is wrong, then they (the doctor) see some result. They are the doctors and they try to help and if I continue to complain, then they are exhausted.

LISA also described the doctor's limitations:

> Doctors try to preserve life. They can't give life. They cannot control how long a person may live. He can't tell.

TINA said:

> I knew that the doctor can only treat my disease, but he can't save my life. God decides when I should leave this world. I only prayed. When I was in doubt or feeling afraid, I prayed.

SUSAN expressed a slightly different idea. She felt that God treated her disease through the hands of the doctors.

It seemed that spending time to explain things is a critical element in gaining patient's trust. When too many physicians are involved, there is a tendency for each physician to focus on only a part of that person. Nobody is looking at the whole person. This can lead to feelings of abandonment by patients. The concept of a team is interesting. JOAN felt betrayed by the system and she felt lost and did not know to whom to turn. JEAN's husband initially wanted a second opinion and was told it was not necessary. He spoke of his feeling:

> My intention was to find out if there was a possible chance of a mistake. Sometimes doctors make mistakes too. I still suspect she didn't have cancer...The location of the lump is not right on the breast. It is kind of underneath. I suspect that it is an ordinary lump. I wonder if they made a mistake with the specimen and were given the wrong result.

At this point of the interview JEAN had just completed her radiation treatment and was taking hormone therapy. This comment suggested that denial was being used as a way for a family member to cope with the cancer.

It appeared that trust was an important element between the physicians and their patients and an important aspect of health care. Having trust in a physician affects a person's ability to cope with cancer. Baider, Uziely and De-Nour (1997), in a study of 205 cancer outpatients in Israel, found several elements that the patients perceived an ideal doctor should have. Ranked highest was trust. Of interest is the lack of information shared in this study about relationships with nurses. Were the wrong questions asked or is there another dynamic at play here?

Reflections on the Findings

The data described the Chinese-Canadian cancer patients' illness experiences. In particular, the data demonstrated Chinese-Canadian cancer patients' information needs and decision-making preferences in cancer treatment. To summarize these data, Frye's (1991) four cultural themes fit nicely and will be used. Frye said that in order to understand the process of health care decision making among an ethnic minority group, the critical element is to identify the cultural themes that surround this behaviour. She suggested four cultural themes: belief about disease causation; pragmatics of the situation; language and cultural factors; and, familism.

Beliefs about Disease Causation

The majority of the participants in this study subscribed to a Western view of cancer causation. Several of the respondents suggested environmental and genetic factors as possible causes of their cancer. Some participants thought stress, emotions and suffering were the reasons for cancer occurrence. One of the participants thought it was luck. Some offered more scientific explanations involving abnormal cell growth within the body, or exposure to environmental factors such as chemicals or the sun. Some thought it might have to do with dietary practices and lack of exercise. Others said they just could not explain it. Some of them offered more than one explanation.

This group varied in their beliefs about cancer causation. Some of their explanations were probably learned from what they were told or what they have read. None of the participants offered a TCM-based explanation of Yin and Yang imbalance or mentioned the Five Elements.

Pragmatics of the Situation

Pragmatics of the situation refer to the health care environment and the ability of people to access care and services. Difficulties of participants in this study were not related to the understanding of Western Medicine. The participants in this study came from societies with pluralistic health care systems and were familiar with the Western medical model. They had varying degrees of belief in TCM. Some of them expressed a desire to access TCM services. Their concern was the lack of financial support offered for the use of TCM in Canada. Another concern is the quality of TCM practitioners. There is no uniform certification process to ensure the quality of these practitioners in Canada. These two factors limited participants' choices in using TCM to treat their illness. The Chinese immigrants, therefore, are confronted with a restriction in their choice of a medical system which they desire and with which they are familiar.

Language and Cultural Factors

Language and cultural factors are major determinants when people decide where to seek help and from whom to seek it. Nine of ten participants had a family physician who is Chinese and who they identified as someone with whom they could communicate. Ability to communicate is the major factor in their ability to utilize existing services and to get sufficient information to make treatment decisions. For this group, their difficulties seemed to be more with language and less with cultural differences.

Familism

Familism is the belief that health care decisions should be made within the family. The participants in this study did not subscribe to the belief of a family model in decision making. Even though the literature suggests that Chinese people believe in family members as health care decision makers, the participants in this study said otherwise.

Summary Statement

There are suggestions in the literature that Chinese immigrants hold certain values and beliefs and that they experience difficulty accessing the Canadian health care system when confronted with illness. The findings of this study, however, suggest that when confronted with cancer, Chinese immigrants' desire for information and their preferences for treatment decision-making are similar to that of the general population. There are within-group differences among Chinese immigrants in terms of education, age, socioeconomic status, language proficiency and belief in TCM. These variations, and not their status as Chinese immigrants, affected their experiences as cancer patients. It is important to realize that differences between Canadian cancer patients and patients who are Chinese immigrants may be the result of individual differences rather than cultural differences.

In the following chapter, the discussion of findings will be extended. The experience of coping with cancer, as perceived by the research participants, will be discussed.

Chapter 6

THE MEANING OF CANCER AND COPING: CHINESE IMMIGRANTS' EXPERIENCES

This study was intended to examine Chinese cancer patient's information needs and decision-making preferences with regard to cancer treatment. The findings suggest that Chinese patients have similar needs and preferences to those reported in the literature. What is different, however, is the existence of a language barrier for some of the participants, and the difficulties which are caused by this barrier. Chinese immigrants' difficulties with the English language vary, as discussed in the previous chapter.

During the interviews, participants spontaneously spoke about their emotional reactions to cancer and expressed their ways of coping with it. This information had not been sought. It came up consistently, however, and became important to explore in order to expand my understanding of participants' experiences with cancer. The focus of this chapter will be an exploration of how these ten Chinese immigrant participants coped with their experiences of cancer.

When persons are confronted with a diagnosis of cancer, initial reactions tend to be a mixture of emotions and concerns. Several questions and concerns come to mind at this time. Patients commonly search for the meaning of cancer and try to determine how it may impact their lives. They also think about what it means to their family and their relationships with them. Patients also search for ways to cope with their cancer. In this chapter, the emotional reaction to cancer is explored, the meaning of cancer for the Chinese immigrants is discussed, the way they cope with cancer is described, and the special issues that the Chinese cancer patients confronted are discussed. It is important to stress that responses varied among participants and few unifying concepts unique to this population emerged.

The Emotional Reaction to Cancer

When a person is confronted with the cancer diagnosis, many emotions appear. A wide range of emotions were expressed by the respondents in this study. These emotions included sadness, shock, worry, disbelief, anger, pessimism and determination. For some respondents, initial reactions included multiple emotions. TINA's and LISA's accounts of their responses to the diagnosis of cancer show the range and mix of emotions experienced.

> When I learned about the report, I felt numb...it was like I was given a death sentence, but I knew I had to be strong. My son was only four and I knew I couldn't die yet....I said to myself that I have to be strong and be hopeful. (TINA)

> I was angry. I thought it unfair that it would happen to me....I felt depressed. But I didn't take it out on others. I kept it to myself...My mood was terrible...I felt like I was given a death sentence. Then I felt helpless, not knowing what to do....The thing I really worry about is my daughter. Whenever I thought about my daughter, I wondered if I might have given her breast cancer because it is hereditary...I became sensitive to my family's health. (LISA)

Some respondents reported strong emotions. JEAN's and JOAN's responses are typical:

> I couldn't believe that I got breast cancer. I always have routine check-ups and I eat a balanced meal. I don't eat herbs like some other Chinese do. (JEAN)

> I was very scared. I don't know whether it has spread or not. I don't know if I will live or die. I felt like I was walking in the dark. (JOAN)

Other respondents expressed their emotions more mildly; "I was a bit disappointed", is how LOUISE expressed her responses.

In their exploration of initial responses to cancer, respondents often spoke of the degree to which the diagnosis had been expected. Both JANET and PAUL spoke of wondering why they would have cancer. LOUISE, on the other hand, said she was not surprised. LOUISE, in fact, reported a sense of responsibility for her situation.

> To have cancer is not so surprising to me. When a person gets older, there is always something that shows up. Life is not always smooth and peaceful.
> It is important to do breast self-examination. If I practised self-examination faithfully, I may be able to discover the lumps sooner and I might still need surgery but I may not need radiation. The treatments would be less and so would the side effects.

A cancer diagnosis is often equated with a sense of loss of control and death (Donnelly, 1995). Cancer diagnosis is also equated with suffering, pain (Ferrell & Dean, 1995; Kahn & Steeves, 1995) and hopelessness (Gordon, 1990).

Upon receiving their cancer diagnosis, the participants often thought about life and death. These thoughts were not necessarily frightening. For some participants, there was a sense of acceptance. SUSAN and LOUISE expressed acceptance and stated that they are not afraid of dying. The reasons given for the lack of fear varied. SUSAN felt that she had already lived a long life. LOUISE thought it was alright to die because of her fulfilment of family responsibilities. There is also a sense of fatalism about LOUISE's appraisal.

> When I found out I had cancer, it was like being given a death sentence.....I am not afraid...I am not worried about dying. Even if I live another ten years, I would be eighty years old and that is plenty old for me. (SUSAN)

> If I am destined to die of cancer, there is nothing I can do. I have no choice. I know everybody has to die. I am not afraid of dying. Today I feel my responsibilities have been fulfilled and even if I die that is alright. (LOUISE)

For some participants, the thoughts about life and death raised a sense of uncertainty and even concern. Concerns about their family and about their own personal commitment to their family members were common reactions. LISA articulated these concerns very clearly when she said:

> I have much to think about. But I didn't say anything about it. I asked the questions and then tried to answer them myself. I also thought about what I might do. I thought about the old and the young in my family. How would I tell them? My youngest child is really young. I don't know what to do. My husband just started this business. He really needs my help. What should I do? If something happened to me, what would become of him?...I want him not to be troubled by me. I know he is worried, but he doesn't say anything. So I choose not to bring it up.

The feelings of uncertainty appear to be ongoing and continue over time. JEAN admitted that she is uncertain of her health and believes that it could change at any time.

> I can't (relax). Not until I reach five years when I will be considered cancer free. There could be changes anytime in the next few years.

One gets a sense from her description that her five-year anniversary, should she continue to be in remission, holds out hope for a reduction in uncertainty for her. This uncertainty can have significantly negative results, as experienced by LISA.

Whenever she contemplates returning to the cancer clinic for her check-ups, she experiences major emotional upheavals.

> I am very afraid of seeing the doctor...My emotions become unstable when it is getting closer to seeing the doctor. I wake up all night. I can't concentrate at work. I only feel relieved when the doctor tells me that it is alright.

LISA also described the stages of her emotions and demonstrated the extent to which the emotional reactions to cancer continue beyond the completion of treatments.

> At first it felt like I was given a death sentence. Then I felt helpless, not knowing what to do. I just followed what the doctor said. After the surgery I felt relieved. But then there would be questions regarding more treatment. The future treatment would seem even more unfamiliar to me. Radiation is foreign to me. I felt I am fighting with death. After the radiation I knew that I was cured. But then I would worry that the cancer may spread to other places.

These emotional reactions to cancer are not unique to Chinese cancer patients. Frank-Stromborg, Wright, Segalla and Diekmann (1984) studied the psychological impact of cancer diagnosis among American subjects, and found shock and disbelief to be common reactions. Krause (1993), in a Finnish study, found two thirds of the participants expressed shock as a reaction. The participants in this study also expressed shock, disbelief and anger. These findings suggest that emotional reactions to cancer are common across cultural groups. The commonalities in emotional reactions across cultures is an important finding and needs to be recognized by caregivers.

Another commonality is the accuracy with which cancer patients can recall their initial emotional responses. Two-thirds of the subjects in Krause's (1993) study had been diagnosed with cancer for more than two years at the time of data collection, and yet they shared similarities in their emotional responses with the respondents in this study who had been diagnosed within a year. This finding suggests that patients' perceptions of their emotional reactions to cancer can be recalled with considerable accuracy over time.

The Meaning of Cancer

The diagnosis of cancer challenges one's belief of human control and one's mastery of their world (Kleinman, 1988) and it implies change, loss and disorder (Haberman, 1995). Taylor (1995) states that the search for meaning involves the attempt to integrate the previous experience of order and the present sense of disorder into a new, more mature model of reality. She further explained that in the process of finding meaning, patients often attempt to explain causation, then ask why it happened to them. According to Taylor, some patients project the blame towards themselves and others, and other patients try to find the significance of cancer in their lives.

Lipowski (1970) described meaning as a subjective interpretation of the significance of disease-related information. Patients evaluated the facts about their illness according to their personal experiences, knowledge, values, beliefs and needs. Chinese immigrants to Canada have unique experiences. They have prior knowledge and understanding about diseases and health issues, they hold certain beliefs and values, and have special needs. In describing the meaning of cancer among them, the explanatory model of cancer causation, and how they feel about disclosing the diagnosis is explored.

The Explanatory Model of Cancer

In trying to explain the cause of cancer, some participants offered multiple explanations. As they explored the multiple possible causes, some respondents seem to have come to a conclusion while others seem to be still experiencing puzzlement.

> I always had a shadow in my head because my mother died of cancer. I

> always had this shadow. Maybe it is hereditary. It could be emotion too....it is from within the person's body. It has to do with the cells inside one's body. It absorbs something and starts to grow rapidly. It may be because of lack of exercise. (JEAN)

> Skin cancer is caused by over exposure to the sun, or both environment and genetics. But lots of people are exposed to the sun. I was exposed to the sun from a very young age on, and many people are the same. Why don't they get skin cancer? But some people claim that everybody has a cancer tendency, and if you are healthy and your normal body cells can control it, then it won't show up. Everybody tells something different. At the end, I think bad luck is what caused it. Bad luck, that is it. (PETER)

Genetic and environmental factors were considered by several respondents. Typically, respondents explored their own histories in the light of common environmental explanations for cancer. PETER, JANET and LOUISE all explored these factors.

> I believe the human body from young to old depends on genetics and environment. What you get from your parents is genetic. If the genes are good, then you are healthy. But environmental factors cannot be ignored either. Sometimes, if the genes are not good, what one does can compensate for it. My environment, my life, my age group suffer a lot...A lot of suffering, when I was young a lot of suffering. (PETER)

> The food that we ate and the environment that we lived in all somehow could cause cancer. I read some books and it said that Asian people have a low incidence of breast cancer. But when they immigrate to another country, such as America, Canada or Europe, their breast cancer incidence increases. So our life style and the environment we

> live in may affect cancer incidence....the body cells change suddenly, that is the simplest way to explain it. (JANET)
>
> It is caused by unexplained abnormal cell growth. I thought about why I have breast cancer. Within my ability to do, I look after my health. I eat well. Before I came to Canada, four to eight years ago, I worked very hard. I ate a lot of barbecued foods. I wondered if it was the food I ate then....it could be stress or long hours of work....or maybe I was born with cancer cells already in me. I don't know why. Maybe because my mother had me when she was in her forties. Maybe my family was poor and I was undernourished...It may be because of the hardship of the war, right after the second world war, everybody lived very poorly. It is hard to know...when I was young there was really no one to take care of me. Often when I was hungry, my neighbour would feed me....or it may be the genes that have caused my cancer. I got a letter from my family that my uncle died of cancer a few months ago. My other uncle and aunt also died of cancer. So I thought it may be genes. According to the books, people with more childbirth have fewer chances of developing cancer of the breast and ovaries. May be it is because I only have one child. (LOUISE)
>
> My great-grandmother (had cancer). She had it when she was in her 80s...I was not too surprised (to have cancer) because the last two years of my life I was under a tremendous amount of stress. I worked. I have not been looking after myself. I neglected all the things like exercise and healthy living. I just worked and worked....it is a combination of genetics, life style and stress...and the environment. I think the environment is a major factor. (JOAN)

PETER and LOUISE spoke of suffering. PETER spoke at length during the interview of the hardship of life in China during the early communist years and LOUISE spoke of the hardship of growing up in Hong Kong. Impoverished living conditions, lack of care, and malnutrition are causative factors that were considered by some participants. Several participants also mentioned stress in their life as a causative factor. These quotes suggest to me that some participants were exploring multiple causes and have not decided which one to believe. Others said that they simply cannot explain it.

> I don't know. I don't smoke and I don't drink. People said it could be the "Feng Shui", but I didn't listen to them. My parents don't have cancer. Last year my sister in Toronto had breast cancer. (TINA)

> I don't know. No one in my family has cancer. I am the first one. (SUSAN)

Despite the participants' attempts to explain the cause of their cancer, they really are saying that they don't know how it happened. They came up with a range of explanations, and in doing so, certain themes emerge. Dodd, Chen, Lindsey and Piper (1985) studied the attitude of patients living in Taiwan and their views towards cancer and found that 60% of the subjects said they didn't know what caused their cancer and 25% assigned long-term stressful situations as the cause. Ten percent of patients in Dodd's study attributed cancer to an accumulation of physical discomfort and an equal number thought that having too many children and poor hygiene or even a bad personality might cause cancer. Only 7.5% of subjects assigned cancer causes to lifestyle factors such as smoking and drinking.

In explaining cancer causation, both groups of participants are similar in their explanation. The participants in this study, however, also spoke of environmental factors, cell biology, and genetic influences. None of the participants in either study used the TCM concept of Yin and Yang balance as an explanation for the cause of cancer. This is surprising as one would assume that Chinese people believe in TCM and the concept of Yin and Yang as an explanation for disease causation but this is not evident in this study or in the one by Dodd (Dodd et al., 1985).

In describing the impact of cancer, Dodd et al. (1985) found that more than one-third of subjects said it was very serious to have cancer, and that there is little hope and they are preparing to die. Others believed it to be a mild disease. Concerns about how cancer diagnosis may influence their emotions and limit their ability to work are expressed. Ten percent of subjects expressed fear of pain.

The participants in this study differed in some ways. None of them trivialized having cancer. They all said having cancer was serious but thought it was treatable. The notion of death occurred in all of their minds. In terms of emotions and pain and how cancer may affect their ability to work, the findings of Dodd et al (1985) are confirmed.

When Dodd and her colleagues (1985) examined how their participants viewed cancer treatment, 55% of them thought that the cancer treatment would be effective in treating their disease, 35% of them trusted their doctors in what needed to be done, 15% said treatment might provide a moderate effect, 15% said other measures could help their disease, and 10% said that treatment would not help. It is not clear how these participants arrived at the treatment decisions or what roles they preferred to play in terms of choosing cancer treatment. The information needs of these cancer patients were not studied. Participants in my study all expressed belief that their treatments would work. The use of TCM was low among the participants in this study, as well as in Dodd's study. Four out of the 15 participants in Dodd's study were receiving TCM for their cancer. It is not clear what types of Chinese therapies were used or how they were used. In Taiwan, both TCM and Western Medicine are practised and are readily available to the people. Only a small number of Dodd's participants sought TCM to treat cancer. This raises questions on how people in Taiwan actually utilize TCM to treat cancer. Participants in this study identified cost, the lack of availability of qualified practitioners, and a lack of confidence in its efficacy as reasons for not using TCM. Perhaps Dodd's respondents shared similar concerns?

As the participants reflected on their past life events and searched for clues for what might have caused their cancer, several patients in my study chose not to disclose their diagnosis to others for fear of what others may think of them. Even though the participants held views comparable with Western thought about cancer causation, they may have regarded having cancer as something undesirable and, consequently, did not want others to know. The participants in this study held a view of cancer causation similar to what is found in the literature. Their feelings towards disclosure of their cancer diagnosis and the reasons for not sharing their diagnosis with others, however, are unique.

Disclosure

The process of disclosing a cancer diagnosis involves several related issues. These issues include who should be the initial recipient of the information about the diagnosis and prognosis. If the initial person is not the patient, then the next issue is who is entitled to know and how much is that person entitled to know. If the initial person is the patient, then the issue becomes what should the patient be told.

In some cultures, the patient is regarded as a sick person who needs to be protected. In these cultures, a family member is commonly the initial recipient of the information about the diagnosis and prognosis. Sometimes they withhold this information from the patient in an effort to protect him or her. Fielding, Ko and Wong (1994) studied Hong Kong Chinese cancer patients' understanding of their cancer diagnoses, and found that the family were told of the prognosis and this information was withheld from the patient in a third of their subjects. It was common for family members to request that the patient not be informed, especially when the prognosis was poor. Li and Chou (1997) discussed communication among Chinese cancer patients in China and found several different practices. Physicians commonly told the patients their diagnosis when the prognosis was good and treatment outcomes were likely to be favourable. Sometimes the physician would discuss the cancer diagnosis and prognosis with the family first. If the family requested that the patient not be told the diagnosis and prognosis, that wish was respected. Ghavamzadeh and Bahar (1997) found similar practices of cancer information disclosure in Iran.

In the North American health care environment, these practices create uneasiness among health care professionals who hold the belief that patients have the right to be informed, to self-determination, and not to be harmed. Davis (1996) interviewed and examined end of life decisions among Chinese-American, Afro-American, Hispanic American and Anglo-American patients and found that there are fundamental differences in the concept of harm and the concept of self across cultures. While health providers in the North American context believe in disclosure as the right thing to do, the families of some other cultures may view it as harmful to the patient. In addition, she suggested that especially in Asian culture, self is viewed as part of the family network. Therefore, the moral obligation to protect the family may be in conflict with the principle of informed consent and open discussion of end of life decisions.

Even though Davis (1996) found non-disclosure to be widely acceptable within the Chinese culture, participants in this study held diverse opinions on the issue. TINA thought that the doctor should tell the patient everything when he is sure of the information. On the other hand, LISA saw the benefit of not telling the cancer diagnosis to the patient:

> I think it is good that Chinese people prefer not to be told their illness. Because that would help get rid of the worry and pressure. The emotional aspects are so great. Constant worry would hurt a person. If a person doesn't know about the illness, he/she can relax and carry on as usual without the extra pressure. She may be happier. But nowadays, it would be hard to hide that information.

LISA described the emotional turmoil of learning about her cancer diagnosis. She also recognized the fact that such information is difficult to shield from the patient. She expressed the conflict of wanting to know and yet recognizing the emotional benefit of not knowing. Still, LISA did not regret knowing her diagnosis. When she was presented with treatment options, she wanted to be informed of her disease and her treatment. She wanted to know.

Disclosing cancer information is not an easy task. The participants stated that they wanted to know for themselves. Perhaps the consideration is when to tell, how to tell, how much to tell, and who to tell. As JANET suggested:

> The person who is optimistic should be told. People like my sister who worried about every little thing shouldn't be told. She would be sick with worry...It is more appropriate to tell the family first and then discuss with the family on whether to tell the person and how much.

Another dimension of disclosure happens between ill persons and their families. When confronted with the cancer diagnosis, patients may not tell family members so as not to worry them. The intent to protect the family is evident. This was observed among the participants. TINA chose not to tell her mother that she had cancer. She said, "I didn't want to hurt her". LISA wanted to protect her family and also did not tell her mother of her cancer. At the same time she realized that this had created a barrier between them. LISA said:

> Sometimes she (her mother) would say she didn't know anything about my health...I think she knows something isn't right. I keep things from her and she keeps things from me too.

Gordon (1990), in describing the implications of cancer diagnosis within the Italian culture, said cancer is associated with such concepts as death, suffering and hopelessness. As a result, disclosing the diagnosis to the individual would be like sentencing that person to a social death. Not disclosing, however, results in secrecy and a separation of the people involved. Gordon described cancer as a disease of "division".

Another level of disclosure is telling outsiders about the cancer diagnosis. This is observed to be uncommon practice among the Chinese. One of the reasons is fear of gossip. JANET expressed the conflict she feels around the issue of revealing her cancer diagnosis to others. Even though she recognized the benefit of sharing information with others, she was afraid that this information would be treated improperly. She described her feelings this way:

> It is better if a person can talk to the others. It is therapeutic to be able to express and it is beneficial to both people...I don't know about the Chinese people though. Some don't like others to know that they have cancer. So I am not sure they would talk about their feelings...I am the same way. If I have a friend from a long time ago and I know her well, then I would speak to her. Other people I don't know too well, I would not tell them. I found they are just curious. Some may speak badly of you behind your back and I don't want that to happen. The Chinese circle in Edmonton is very small.

JOAN affirmed such feelings:

> Not all the friends are really concerned. If I know that person really cares, then I would tell her. But some people are just curious. They are not really wanting to help, just curious. And then they would tell someone else. They gossip. That is why it is easier not to tell...when I have experienced pain, I understand it. If I was to tell people who have not had the experience of suffering, they would not understand. So I chose to be anonymous.

JOAN spoke about the potential benefits of disclosing to someone who would understand. It appeared that participants were not opposed to disclosure completely, but rather they only wanted to make sure that they would tell the right person. The right person would be a good friend, someone who was genuinely concerned, and someone who would understand.

Disclosing cancer diagnosis is a complex issue, whether the disclosure occurs between physician and patients, or between patients and family, or between patients and friends. The participants are really saying that there is no best way of dealing with this issue. They are also suggesting that there are many considerations within the larger issue of disclosure.

Having cancer is a threat to a person and evokes emotional response. In trying to understand how cancer may impact their lives, the participants also devised strategies to cope with the disease. In the section that follows, participants' ways of coping with cancer will be explored.

Coping with Cancer

Coping is defined by Lipowski (1970) as "all cognitive and motor activities which a sick person employs to preserve his bodily and psychic integrity, to recover reversibly impaired function, and to compensate to the limit for any irreversible impairment" (p. 93). He further explained that the determinants of coping are intra-personal factors, disease related factors, and environmental factors. The intra-personal factors are the person's age, personality, intelligence, specific skills, values and beliefs, emotional states and cognitive capacity, previous life experiences, and the meaning attributed to the diagnosis. The disease-related factors include type, location, onset, progression, seriousness, and functional impairment resulting from the disease which affect the person's coping ability. Environmental factors can be both human and non-human and include the social support network that surrounds the person.

The Determinants of Coping

One of the determinants of coping is the intra-personal factor. The person's previous life experience and their way of dealing with these life events affect their ability to cope with cancer. TINA had cancer twice in the past and she was more familiar with the cancer diagnostic and treatment procedures than were any of the other respondents. She has utilized the Canadian health care services in the past and was more aware of what to expect. Being familiar with how the system works helped her to deal with her current cancer experience. On the other hand, a person's coping strategy with life crisis in the past may be the one that they continue to use. SUSAN revealed past experience with personal hardship and her faith in God as important to how she now copes with life crisis:

> When I lost my son, I was very sad. Life was grim. I wanted to die. When I came to Canada, someone told me to go to church and I wouldn't. I had no interest. I wanted to let fate take its course. My friend said that I should go to church as God is fate...After I chose God and believed in him, I was a different person.

SUSAN has kept her faith throughout her cancer treatment. Similar to how she dealt with her previous loss in life, she depends on her religion for support. LOUISE spoke of her past difficulties in life and being accustomed to drawing on her own personal strength to deal with life crisis.

> My mother is illiterate and when I was in my teens I already looked after everything for my parents. My father was always ill and often in the middle of the night I had to call a taxi to send him to the hospital. I had to go home by myself. I would be walking home at 3 a.m. by myself and I wasn't afraid. So whenever there was problem, I had to deal with it myself.

Other intra personal factors are values and beliefs. Some participants exhibited a belief in fatalism. Comments such as "fate, God's will, it is meant to happen" were expressed quite frequently. LISA, referring to her cancer, said, "It is hereditary. What can I do? It is fate". SUSAN used the phrase, "If it is God's will" in our interview. PAUL, too, spoke fatalistically, "If it was meant to happen, what can I do?" These quotes illustrate a sense of life's events being out of one's control.

Jenkins and Pargament (1988) studied 62 cancer patients' perceptions of their coping resources, and found that perceived personal control and God-control correlated positively with adjustment. People who believe in God were found to have higher scores in spiritual well-being (Fehring, Miller & Shaw, 1997; Mickley, Soeken & Belcher, 1992). Religious faith and prayer are found to be important coping strategies reported by cancer patients and their mates (Gotay, 1984). About 50% of the participants in this study considered themselves to be Christian. One of the participants became a Christian after diagnosis. These findings suggest spiritual values may contribute to coping with a diagnosis of cancer.

The other determinants of coping are disease-related factors. Disease-related factors include the stage of the disease at diagnosis and the prognosis, as well as treatment related outcomes and the physical condition that accompanies treatments. Different strategies may be employed depending on how sick persons feel and what energy they have. When people are really ill, they may not choose strategies that expend a lot of energy. Their ways to deal with cancer diagnosis may differ from patients who are physically well and at an earlier stage of the disease.

Environmental factors, including human and nonhuman factors, are additional determinants of coping. Social support and financial resources are examples of such factors and will be discussed later.

Coping Among the Chinese Patients

Having cancer is a crisis and a threat. Having cancer not only implies a physical deterioration, it also implies a psychological stress. Lazarus and Folkman (1984) defined psychological stress as "a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being" (p.19). Coping is the process through which the individual manages the demands from the stressor and the end goal is to restore and to maintain the individual's wellness.

Lazarus and Folkman (1984) described two types of coping, problem-focused coping and emotion-focused coping. Problem-focused coping includes strategies that manage or alter the problem that causes stress. Emotion-focused coping includes strategies that regulate the emotional responses to the problem. In other words, problem-focused coping is the person's way to deal directly with the problem and emotion-focused coping is that person's way of changing the impact of that problem on his/her emotions, therefore restoring equilibrium. Data suggest that the participants used both groups of strategies to cope with their cancer diagnosis.

Problem-focused Coping

Problem-focused coping strategies are directed at defining the problem, generating alternative solutions, weighing the alternatives in terms of their costs and benefits, choosing among them, and acting accordingly. Problem-focused strategies chosen by the participants included information seeking, therapeutic use of foods, seeking medical advice and follow up, modifying activities, and seeking alternate gratifications.

Information Seeking

Information seeking is a way to cope with the cancer diagnosis. As previously discussed in Chapter Five, the participants actively sought out information and asked questions about their cancer and the treatments.

> Find out what you need to know and follow the doctor's suggestions. I like to hear the Chinese radio on various health topics, topics on life, family, or general knowledge. (JEAN)

> It helped me to cope if I knew more about it, like knowing what radiation is and its side effects. It also helped if I knew what type and stage the cancer was. Also knowing what treatment was out there helped me cope and reduce anxiety. (LOUISE)

> Information gathering is important. Getting information will help a person prepare for the situation. (JANET)

Information gathering is a way to cope with the cancer diagnosis and was seen as useful and necessary. Not all participants, however, saw information gathering as a way to cope. Some chose to deny information. LISA described wanting just basic information about her diagnosis and treatment from the doctor. She did not seek out information on her own. As she said, "I could look it up if I wanted to. But I didn't want to. It is already in the past. I don't want to rethink it. I just did what I was told".

Therapeutic Use of Foods

The participants used different strategies to promote and maintain their health. One such strategies was the use of foods. As described in Chapter Five, the participants chose certain foods and some of them used herbs to promote health. The belief in TCM and the therapeutic use of foods was not equally shared by the participants. Some participants believed in the western concepts of nutritional balance. JEAN explained:

> We focus on the balance of foods. We are like the Canadian, we eat everything and there is no restriction. I didn't do what some Chinese do, to prepare special foods. I followed the Western way of medicine. The doctor said to drink more water and juice and so I drank more juice. Sometimes I drank soy bean milk. I didn't believe in herbal medicine. I didn't take herbal medicine in Hong Kong.

But SUSAN saw a herbalist and she took herbs to cure cancer. SUSAN said:

> After the surgery, someone told me certain foods are good for cancer, I would eat it. ...vitamins, so the immune system gets stronger...or Chinese herbs, the kind that could kill the cancer germs. 'Hau tau ku' is good for cancer. It is good for preventing cancer in people who don't

> have cancer. But in people who have cancer, this mushroom will kill the cancer germs.

The belief in TCM and the belief in the therapeutic use of foods varied among the participants. This variability cannot be explained by length of residence in Canada alone. Other factors may be involved. Such factors include the country of origin, previous experience with TCM, and the level of understanding of TCM concepts. This variability is evident even among Chinese within their own country. As previously studied by Dodd and her colleagues (1984), only a small number of the Taiwanese participants in her study reported use of TCM.

Seeking Medical Advice and Follow Up

Seeking medical advice is one of the things the participants did to promote their own health. Maintaining follow-up appointments was mentioned by the participants.

> (He said) I just need to see my family doctor every three to four months. He said that I should do breast self examination every month. He said to check both sides. And the remaining right breast I have to do mammogram every year. But everything else should be alright. (TINA)

> The main thing is check up. Early diagnosis would allow for better treatment outcome. When I was told to go for a check up every three months I would do it. I would listen to the doctor. (LISA)

The cancer patients relied on follow-up with health care professionals as a way to cope. Follow-up signified connection. Being connected made them feel more secure and was important to the respondents in this study. LOUISE expressed it in this way:

> The nurse at the cancer clinic gave me her card and said that I could call her anytime if I have any problem or if I need information about follow up. She said if I need a ride to the clinic that I could phone her two days ahead of time....having someone that I could phone, such as the volunteer workers or nurses, would help me deal with having cancer. Or having the home care nurses so I can ask questions and find out what to do.

The lack of follow-up was seen as abandonment and caused anxiety in the respondents who were not provided with follow-up services. JOAN described her dissatisfaction:

> He just said from the report there is no follow up, no radiation. He said there is no follow up. So even if I suffered pain, I cannot go there... I had breast cancer and I had a mastectomy. Everything happened so quickly...The stay in the hospital was too short.

The need for follow up is individual. JOAN was expressing her need for a chance to return to the cancer clinic to discuss her concerns.

Relying on the physician's expertise and following the physician's advice were also ways to cope with illness. The participants expressed the importance of trust towards their physician.

> We should trust the doctor...I try to see the doctor who can help me. I won't give myself pressure. If a person wants to stay alive, she must be strong and accept the recommendations of the people who know. Not to rely on her own preferences. Because even though a person may be very knowledgeable, they are still not as knowledgeable as the doctor. (TINA)

Trust is described as an important factor in patients' coping with illness (Ridder, Depla, Severens & Malsch, 1997). TINA described her view that trusting the physician's expertise and allowing the physician to make the decision is a way to cope with cancer. It is true for some patients that asking them to be involved in the treatment decision-making can add to their anxiety level and "give them pressure", as TINA described. This may partially explain why the majority of patients reported a preference to have the physician make the decision.

Modifying Activity and Seeking Alternate Gratification

Taking action to promote health also means rationally modifying activities. Resting, taking a walk, practising 'Tai Chi Churn', and eating proper foods are self care activities aimed at promoting health.

> It is my own responsibility to stay healthy...getting plenty of rest, eating proper foods and keeping your mind healthy. Healing does not depend on only the treatments. The person's body, the healthy mind is important too. The mind heals 70% and the treatment heals 30%. It is up to the person to master that. If a person has a healthy mind, then he lives longer...I go out every day now. Besides, sitting around too much, a person tends to think silly thoughts. It is nice to go out. (PETER)

> This foot massage can cure many things. My hands were numb, my ear's balance was off, this foot massage cured them both for me. I practised the 'Tai Chi Churn' and I did it every day. I would continue to do arm exercises to strengthen this arm. (SUSAN)

Modifying activities also implied establishing new priorities. Taking care of the self became a priority. It also implied balancing work and rest and leisure activities that are enjoyable.

> Before I didn't have the time...now, since the surgery, I did very little and I have the time to look after myself. I put the housework secondary...I read and I try to get to know my body... to practice breast self examination... I have a friend whom I go out with. We go for tea or shopping. Sometimes I went with my husband for walks around the park by the river. (LOUISE)

> I now worked half a day. I wanted to work. Sitting at home made me bored...It is better to work part time and get some rest in the afternoon. This way I have energy to deal with the evening work like preparing a meal. (LOUISE)

Work is seen as a refuge in coping with cancer. Participants are expressing a view that work may serve as a diversion. They also thought of ways to balance work and rest so as not to exert themselves.

Finding substitute gratification is doing things that one finds enjoyable. Seeking positive comments, creating hope, and planning a vacation are all ways to gratify oneself. LISA found gratification in the expressed views of others, "If they tell me that I look better, I feel good". PETER was planning to get gratification through a vacation that involved travel, "I hope to have a few more years...I thought I will wait a while and if everything stabilizes, I would like to go back to China and Hong Kong for a holiday".

Emotion-focused Coping

Emotional-focused coping involves strategies that deal with the emotions occurring immediately following learning about the diagnosis. Emotion-focused coping includes strategies that aim at diminishing the emotional impact of the cancer diagnosis. In other words, changing one's view towards life, finding positive meanings with cancer, and assigning values to the diagnosis are strategies that can buffer the emotional impact on the person. The participants expressed having cancer as an opportunity for personal growth, and a chance to re-evaluate their lives and revise their priorities. They expressed changes in their world views. JEAN spoke of the unpredictability of life and a philosophy of living day by day while TINA described a wish to enjoy life, to forgive and to help others.

> I feel that life is ...unpredictable and you never know what will happen next...a person doesn't have to look too far ahead. (JEAN)

> Now I thought, I better eat whatever I want, spend the time the way I like...I learned to care about people. I would go and visit my friends who are sick. I shared my personal experience with others and comforted them. I try hard to forgive people who fault me. I don't carry grudges. Even if people treated me badly and happened to need me later, I would still help them...I don't know how long I will live. I try to help people whenever I can. Thinking this way helps me shift the focus. (TINA)

The wish to enjoy life and to help others was expressed by other participants as well. PETER and JANET spoke of their feelings:

> I joined the church's celebration for the seniors. Sometimes I just watched the others participate in different activities. I only want to live day by day. I don't think too far ahead down the road. I better eat whatever I want, spend the time the way I like. (PETER)

> I should enjoy things as they come, eat, live and be merry. I told my sister. Life is too short and I don't know what will happen to me, so we should enjoy life as it comes. We should live and be happy. It is not good to live a short and miserable life...That is not to say one should live a meaningless life. A person can still be productive and live

> a meaningful life and be happy. I love to read. That is how I spent my time. I thought about doing some volunteer work at the cancer clinic. I think I can help the people who cannot speak English or communicate. That would be meaningful. (JANET)

JOAN spoke of establishing new priorities in life and learning to take care of herself.

> I am more focused on health and am able to listen to my body better...And I am less focused on materials. I am not as concerned with money. Health and freedom from illness are the most important things...I learned to listen to my body and take care of myself...I still work hard...I need to remind myself not to overdo it.

PETER described his new found belief in God and SUSAN stated that her faith had strengthened since her diagnosis:

> It is important to believe. We don't have to be afraid...Everything is pre-arranged. You will know when it happens and there is no sense thinking about it. When I prayed with the others I had my own prayer. I feel relaxed about the whole thing now. (PETER)

> I have learned to be patient and wait. In God's word, he said, ' Your patience now is the preparation for to-morrow's work'. (SUSAN)

The participants expressed a variety of changes in how they viewed their lives. They tried to assign meaning and value to their lives and, in doing so, the emotional impact of cancer diagnosis was blunted. Assigning positive meaning to the situation is also included as one of the coping strategies reported in a study of American subjects by Gotay (1984).

Another way to cope with their emotions involved comparing their own situation with others who may or may not have a good prognosis. Comparisons with others may modify the emotional response to a cancer diagnosis and help with coping. Several participants in my study described their coping with cancer by reiterating other people's success stories.

> My mom had stomach cancer...He (the doctor) did surgery on her and told us that even with surgery her chance of survival would not be so great. But she lived for eighteen years after that. (JANET)

> When I was at the cancer clinic, another woman came to talk to me and I have forgotten her name. She came to say that she had breast surgery in 1989 and in 1991 she had the opposite breast removed and now she is doing well. (JEAN)

> A long time ago, when I was a young girl, I knew a single woman who had breast cancer and later she had it removed. She received some treatment. It was twenty years ago and she is still living. (SUSAN)

> I have relatives who are in the same situation (had cancer). Their doctor could not commit to saying what the possibility that they would be cured. But I have seen them do well for many years. They continue to function like before. I feel confident that some people do recover completely. (LOUISE)

Comparing themselves to others who have a good prognosis gave respondents hope that they too might have a good prognosis. Having hope is important in one's adjustment to a cancer diagnosis. Herth (1989), in her study of 120 cancer patients, found that people with high levels of hope devised more ways to cope with their cancer diagnosis.

It is also common that people with cancer compare themselves to someone less fortunate. By comparing themselves to others, the participants elicited positive feelings about themselves. JOAN, in describing someone she knew who had cancer and has since died, said: "When I compare myself to other people who have died, I am lucky".

SUSAN stated:

> In my church, there are two people who have breast cancer. One of them is a teacher. She had a lesion that was weeping and draining fluids. It drained for over a year before she went to see the doctor...She was in the rural area. There are doctors but not a specialist. But she didn't even see the regular doctor. She thought she might have scratched herself and that was why it was draining. Both the woman and her husband said the same thing. It wasn't that at all... She didn't know....She was careless. I know of one person who had breast cancer (in Malaysia) about the time I came to Canada...she is dead now.

How this process of downward comparison (comparing to people who are worse off) influences coping is not clear. Jenkins and Pargament (1989) suggested that downward comparison may enhance self-esteem.

Social Support and Coping

Lipowski (1970) said social support is one of the determinants of coping. Other literature suggested that social support may enhance the person's ability to cope with the cancer experience (Broadhead & Kaplan, 1991; Dunkel-Schetter, Feinstein, Taylor, & Falke, 1992; Krause, 1991; Northouse, 1988). Kahn (1979) defined social support as the expression of positive affect toward another person, affirming another's behaviour, perception and expressed views, and the giving of symbolic or material aid to the person. Lu and Chang (1997) suggested four components of social support;

material and tangible support, emotional support, informational support, and social participation. The participants appeared to place considerable emphasis on emotional support. Family, relatives, friends, and even casual acquaintances they met in the cancer clinic were seen as sources of emotional support. The experiences were described as follow:

> From the discovery of the lump, he was with me all the way. He supported me the whole time. The family is the one who support, comfort and encourage...more importantly, it is the emotional support. Having someone to care about you is better than having medication. (JEAN)

> Family support is of critical importance. Having someone to discuss things with helps a person deal with life's problems. It is important to be together. The concern and care that my family shows are important. It makes me feel good. It is good to discuss things with friends. Being able to express or talk to someone is important and helpful. But one has to select the proper listener. The listener has to be one who is empathetic and patient. Keeping it inside is not good. (JANET)

While some respondents saw support from their family members as important, others, such as LOUISE, felt differently. LOUISE did not feel the same level of support from her family and tried to trivialize its importance:

> My husband doesn't think that breast cancer is a serious thing. He said it is only the skin. He doesn't bother to think about what could happen, like metastases, that could affect other organs and be fatal.

> Maybe Westerners think it is important to have family support. I don't know....My husband is different. He doesn't like to deal with this kind

> of thing. Maybe he is scared.

LOUISE found support from other cancer patients, some of whom she met at the cancer clinic while receiving treatment. She said:

> We visited with one another. They are like my friends. We tell each other how we feel....We are not worried about telling each other things. We were all in the same boat. We share with each other and we express concern for one another....We share our feelings and the information about our diseases. We don't mind sharing. We got to know one another since we saw each other for some time. We also greeted each other and shared information about our treatments, its side effects. We talked about our pain and fatigue. We talked about happy things too.

LISA reported similar experiences and found support from people who were also receiving treatment at the cancer clinic. She described:

> We sat around and talked. We asked each other questions. We saw each other every day. We shared each other's happiness.

Social support is a well studied subject. Stewart and colleagues (1997) studied patients with ischemic heart disease, and found seeking social support to be one of the most frequently used strategies in coping with the illness. She also found that the more frequent sources of social support were family members, close friends, and health professionals. While family members and friends are seen more as the providers of emotional support, health professionals are seen as sources of informational support.

There is literature to support the importance of social support for a person's wellbeing. Lu and Chang (1997) studied 172 elderly persons in Taiwan, and found that, aside from physical health, perceived social support had significant impact on life satisfaction among the elderly. Ngan, Tang and Lau (1994) studied 115 women with gynaecological cancer in Hong Kong and found that 72% of their participants perceived good emotional support from a spouse and 28% from family and friends. Lindsey, Dodd and Chen (1985) studied 40 cancer patients in Taiwan, and found that participants considered their spouse to be the most important source of support with family and friends regarded as of secondary importance.

The participants in this study viewed their spouse, family and friends as sources of support. This finding is congruent with what is found in the literature. Casual acquaintances, such as people who were receiving cancer treatment at the same time, however, were also viewed as sources of support by several participants, supporting what Kahn (1979) described as social support which affirmed the person's point of view. It seems that information sharing and mutual understanding are important aspects of perceived support. Therefore, organizations such as "Reach to Recovery" and "Can Surmount" which are attended by people who have cancer are seen as good sources of support. The participants voiced their opinions on the benefits of support groups.

> There was an organization called "look better, look smart". I have a friend who joined them. She had to have surgery, radiation and chemotherapy and she joined this organization. There was a cosmetic company who sent over products and people to teach these women about make up, about ways to make themselves look better. The cosmetic products are the popular kind. There were many samples. They taught makeup as well as ways to apply turbans using scarfs. They also taught skin care because radiation and chemotherapy would affect the skin and make it dry. They introduced different skin care products. I didn't need chemotherapy and perhaps that is why I was not told about this group...I would (join this group) if the time was right. (This kind of) support group would be helpful. (LOUISE)

JOAN attended a support group and workshops and felt quite positive about them, saying "The workshops are different; they talk about prevention". Not everyone shared Joan's feelings about support groups. JEAN expressed her opinion this way:

> If this group is made up of Chinese women, there will be a deeper feeling, a sense of belonging. This is what I think. Maybe it is the language that is the problem. If I take my husband to the group meeting, it may be uncomfortable for him with all these women around. It is not convenient. That is why I didn't attend the support group.

It seems that participants' views on support groups varied and that language and culture may be barriers to using such groups.

Coping with Pain

The majority of the participants were managing their treatments and their side effects well except for a few who suffered pain following surgery. They described their pain experience.

> I didn't feel pain before. But gradually, I felt discomfort, about six months later...It was not sharp or severe pain. It was more like 'nagging, pins and needles' kind of discomfort. It felt tight in my arm, especially when I used it. It felt like arthritis, not pain but discomfort. (LISA)

> I had to take pain medication for two months. I took 55 pain pills. I needed them for the pain. But then I wondered if the pain medications would be harmful to me...there was still a bit of pain. The pain is on both sides. I think it is from the surgery. It feel like it is from the

> inside. The pain wakes me up in the night. It isn't severe pain. It feels tight. The pain is tolerable. It feels like pins and needles sometimes. It comes and goes. (LOUISE)

> Up to now I still have pain...I had so much pain and I suffered so much...The pain bothered me the most. I have pain every day and every minute. This physical pain no one can help me. According to the clinic, it is not cancer related. So it is not their responsibility. My family doctor doesn't know what to do with me...This pain is from the nerves being cut. There are nerves that connect to here, here and here... I went to a physiotherapist. She is so good. She found out my skin was so sensitive. I could not wear a bra. At first I couldn't wear it at all. She said the first thing to do was to become desensitized. She said to use the shower to spray and desensitize the area....So far I talk to the woman from Reach to Recovery about my pain and she doesn't know how I feel. I told them about my pain and they have never experienced it. When I don't have pain for one day, I am thankful. (JOAN)

JOAN attempted to make sense of her pain experience:

> Religion is important... the spiritual care...it may be that I was given the pain as well as blessings...The grace I received from god is enough for me and with that I was given pain. I have lots of blessings from God.

Pain is described as a subjective experience that others would not necessarily understand. PETER described his pain in the following way, "They (the nurse) could give me injections and give me medications for the pain. They didn't really know the suffering I was going through".

SUSAN described her fear of pain:

> I am old now and I am not afraid of dying. I prayed for God to save me from pain. I said I would be obedient to him. I am very afraid of pain. I asked God not to give me pain.

The participants' ways of coping with cancer are evident in their descriptions. Their coping is similar to what is described in the literature regarding cancer patients as well as that relating to patients who suffer from other chronic illnesses. Chiou, Potempa and Buschmann (1997) studied Chinese patients who suffered myocardial infarct, and found that they used positive thinking as one their coping strategies. This strategy corresponds to emotion-focused coping. Shih and her associates (1998) found that Chinese cardiac patients in Taiwan frequently used problem-focused coping methods, learning to take care of their own health, appropriate exercise and seeking help from others. They also used emotion-focused coping methods such as accepting the truth, positive thinking and assigning it to fate. It seems that the Chinese patients in this study chose similar strategies to cope with their cancer.

The data described so far suggest that Chinese cancer patients have much in common with the general cancer population as described in the literature. They share similar emotional reactions to cancer, assign similar explanations to the causes of cancer, and cope with cancer in similar ways. There are issues, however, that are unique to Chinese cancer patients and these differences are described in the next section.

Coping with Special Issues: the Chinese Immigrants' Experience

Chinese immigrants have unique experiences to share. Some of them have family remaining in their native countries. The existence of family members in the country of origin can affect the emotional responses to the diagnosis of life threatening illness. PETER, JOHN and PAUL all have children back in China who are not permitted to leave. They realized they may not see them again. They described their experience:

> I was really sick (following the radiation), I had no energy left...The pain make me...I couldn't think. I thought my son from China was coming. I asked about him frequently. I was confused. I kept asking why he wasn't here. I thought I was going to die. I was going to make the final arrangements. I couldn't think about anything else. But I still hoped that there was a chance I would be cured. (PETER)

> Since I got sick, we phoned them twice. I just keep thinking about my children in China. I am worried about them. (JOHN)

> I just want one of them to come and see me. I would like to be able to go there for a visit. My health may not be good enough to travel on my own. I would like to see my family. Even if one of them could come, it would be nice...They are not permitted to leave. They wanted to come but couldn't. (PAUL)

Another unique experience that immigrants may be able to offer is that they are able to compare the two health care systems; the one they left behind and the one they are currently experiencing. Such comparisons help us to see our health care system through their eyes. We may learn to value certain aspects of our health care system as well as to see opportunities for improvement. The participants described their views as follows:

> In China, if a person is in the hospital, he/she has to hire a private nurse in order to get proper care. Otherwise you could be ringing the call bell and no one would come...The nurses just follow the doctors' orders. And they don't care what it did to me...That is the only cancer hospital and you have to go and line up early in the day in order to get

> seen. And it costs money. And if you cannot pay then your service will be delayed. The people who can pay may get in first...If the person is too sick or too serious, they (the doctor) may not see him/her. They just give them some medication, any medication, and send them home to wait to die. (PAUL)

> Here in Canada the health services are really good. When there is financial hardship, health services are provided according to income (referring to AADL). If a person's income is low, there is no charge. This time I was ill, if I was in China, the expense would be phenomenal. (PETER)

PETER identified other issues:

> (Here) language barrier is the biggest thing. The second thing is the medication. A person has to get their medication and that is inconvenient. The problem is not the language, it is the price of the drugs...In China, it is changing too. The benefits are not as good. The same for hospitalization. There was no payment before and now there is payment. They have to change. You see a lot of wastage here in the hospital. I couldn't eat, but each time they brought me food, and ended up throwing it out.

JOHN also compared the cost of health care in China with that in Canada:

> It would cost a lot of money in China...In China, you have to pay the money upfront. Surgery for cancer costs a lot of money. Many people depend on money from overseas to compensate for their daily expenses. And if they don't have that extra money coming in, life is pretty tough. In Canada it doesn't cost anything. (The service here) is better than

> China. More thorough in their service. My sister came from the U.S. to visit us and she said that it also costs lots of money in the U.S.

JOHN also spoke of how he would behave differently if linguistic barriers were removed.

> If I knew the English language, I would ask what kind of cancer and ask to see the tumour. In China, the doctor would show you what they removed. They would explain to the family so they understand about the disease. In China, the family gets to see the removed tumour too. I have a relative who had surgery in China and I got to see what was removed...some of my relatives can speak English and he didn't tell them much either...before I left the hospital he examined me and told the Chinese doctor that I could go home. He didn't tell me anything.

JOHN perceived the communication barrier as a major problem with health care service in Canada, but he added, "Despite the communication barrier, we were treated with respect".

Other issues, such as financial worry, are common among Chinese cancer patients. The research participants came from diverse backgrounds and their financial situations vary. Some of them are affluent and some of them are just getting by. Many immigrants come to this country by way of sponsorship and the feeling of dependence is significant. JOHN described his experience in the long term care facility:

> Just my son-in-law works. One person to feed seven of us....I had to pay $800-900 a month. I said that I couldn't afford it. I had no income. I am now dependent on my children....Having to pay for my two meals a day is fine. Having to pay for this expense is too much to ask for.

Even though the Chinese immigrants who came to this country by sponsorship felt that they were a financial burden for their families i.e. children, their contributions should not be ignored. JOHN's wife was able to secure employment and help the family financially. PAUL's wife babysits all three of the grandchildren so that her daughter and son-in-law can both work. LISA lives with her mother who babysits for her while she works.

Reflections on the Findings

The Chinese immigrants who suffer cancer share many commonalities with what is observed in the general population as reported in the literature. Their emotional responses to the cancer diagnosis, their perceptions of how cancer has impacted their lives, and their ways of coping with cancer are similar with what has been found in the research on North American populations.

There are also unique issues. The Chinese population comes from diverse economic and political backgrounds. Concern with finances and family separation were expressed by some of the participants. Language barriers inhibited information sharing. Some participants would have preferred greater access to TCM. In the following chapter, the study findings are summarized, possible meanings are explored, and implications for nursing are suggested.

Chapter 7

IN THE CONTEXT OF CROSS CULTURAL CARE: FINDINGS, MEANINGS AND SIGNIFICANCE

While this study began as research to explore the information needs and decision-making preferences of Chinese cancer patients who are immigrants to Canada, it has become much more. Why has this happened and what does expanding the parameters of the original research contribute to our knowledge about this patient population? What is the significance to nursing? In this, the final chapter of the thesis, these questions are addressed. I begin with my story.

"Why Don't You Ask Her?"

It was on Labour Day in 1970 when I first set foot on Canadian land. I arrived in Vancouver and from there I took the Greyhound bus to Edmonton. The bus ride was eighteen hours. Having left home for the first time, I felt lonely and frightened. I never spoke a word the whole time. I heard a voice behind me asking her companion, "This lady has not spoken a word at all, is she deaf and dumb"? The other replied, "I don't know, why don't you ask her"?

I settled in Chinatown, where rent was the cheapest. I met other Chinese people. Many of them were seniors. I was saddened by how they lived in isolation and loneliness, without community support. I wrote to my mother and asked to go back to Hong Kong. I didn't want to stay. My mother replied, "My daughter, you have to stay. It is good for you there. You have to try harder". So I stayed, but I stayed away from Chinatown.

Years passed and I have acquired the English language and a permanent job. I started a family. Things have improved for me. Deep in my heart I wondered how the Chinese seniors were doing. So I returned to Chinatown. I found that their living conditions had improved. But more work needed to be done. So I stayed in Chinatown.

For me, things are different now. Having a second language is an asset. Sometimes I am asked to be an interpreter for Chinese people who can't speak English. Sometimes I am asked to give advice on nursing care problems. "How do I take care of this Chinese person? What do you think is important to her"? And my consistent reply is, "Why don't you ask her"?

Returning to Chinatown in 1991, I intended to examine issues relating to the health of Chinese immigrants. Having been a Chinese immigrant, I feel a certain closeness to them. Around the time I was taking the Oncology Nursing Certificate at the cancer clinic, I became aware that certain cancers are more prevalent among the Chinese. During my four months there, I met many Chinese people. I was aware that some of them were struggling with their cancer treatment and its side effects. They demonstrated little understanding of their treatments and their sequelae. I was not able to determine whether these difficulties were due to cultural differences or situational factors. This prompted my interest in studying the information needs and decision-making preferences of Chinese cancer patients.

My personal interest in the needs of Chinese immigrants was further prompted by the lack of research on this group. Furthermore, existing literature that describes them seems somewhat removed from reality. Cultural information about Chinese health beliefs, values and customs that I read in the literature often seem alien to me. My assumption is that since I am Chinese, this information must be about me. Why do I feel that some of the descriptions and conclusions are untrue? I wondered if other Chinese people feel the same way I do. I became aware that being Chinese does not make me an expert in what Chinese people are like. Still, I suspected that the existing literature did not necessarily provide accurate information about this population of immigrants to Canada. I realized that I must ask the questions, as should other health care professionals. What do we know about the Chinese people we serve? How closely does the existing literature describe them? When they are confronted with cancer, what issues confront them? Do Chinese cancer patients have special needs? What are the Chinese cancer patients' decision-making preferences and information needs when faced with cancer treatments? These were the questions for which I set out to seek answers. What I found is summarized and tentative meanings are explored in the remainder of this chapter.

Overview of Key Findings

The key findings are organized into three areas. Thus cancer treatment decision-making preferences and information needs, coping with cancer, and special issues of the Chinese cancer patients participating in this study are discussed.

Treatment Decision-making Preferences and Information Needs Regarding Cancer Treatments

In terms of cancer treatment decision-making preferences, most participants in this study preferred to have their physicians make decisions for them. Furthermore, reasons for their willingness to delegate the treatment decision-making responsibility to their physician were given, including trust in the physicians' expertise, their perceived lack of knowledge to make the decision, and their perception that by delegating the decision-making responsibility, the pressure on themselves was alleviated. Only two out of ten participants chose cards that indicated a preference to make their own treatment decisions. These two participants were women, younger and of higher socioeconomic status and educational background than other participants, with sufficient English language skills to communicate needs and understand explanations. They valued personal control over their health and described a similar style in managing previous life events. It seems, however, that their preferences for involvement in treatment decisions were exercised only when their opinions were solicited and that choices were not presented uniformly at all stages of their illness.

When the participants were presented with the cards that described the five decisional preferences, they seemed able to select their preferences from among the choices, but added qualifying statements such as, "it is not that simple" or " I have to trust the doctor first" or "he has to tell me what he wants to do". What seems evident is that the pattern of decision-making preferences of this study population fits with that of research on "mainstream" Canadian populations and that the cards may not capture the complexity behind decision-making preferences. For example, it was not unusual for a participant to choose a card and then make qualifying statements that seemed closer to the option presented in another card.

What was surprising was that even though the literature suggested that Chinese people typically involve family when making health care decisions, the data did not support a family decision-making model. Additionally, what is described in the literature about the Chinese people being respectful and submissive towards authoritative figures to the degree that they would not challenge the physician's recommendation is not supported. Some of the participants in this study were able to ask questions and seek answers from their physicians. They would agree with the physician's choice only when satisfied with the physician's explanation of why the options was being recommended.

In terms of information needs, all of the participants expressed a desire to be informed of their disease, treatment options and potential treatment outcomes. Not all of them, however, had the ability to understand the information given to them due to language barriers. From what they shared in the interviews, it became evident that it was linguistic barriers and not cultural barriers that posed the greatest difficulty.

Participants described cancer etiology in terms equivalent to the Western biomedical model rather than Traditional Chinese Medicine. Thus, with adequate explanation, in terms and language that they understand, adequate communication of information is achievable. That in many cases patients misunderstood or lacked information was an issue, but cultural differences did not appear to be the reason.

Coping with Cancer among the Chinese Patients

Participants voluntarily expressed what having cancer meant to them, including the impact it had on their lives. They also expressed their ways of coping with cancer and cancer treatments. What they shared is similar with what is reported in the research literature of "mainstream" populations in North America. What was different were the views expressed about the utilization of TCM and the use of food in promoting health in general or as it related to cancer. Concerns included the difficulty of finding qualified TCM practitioners and the cost of using such services. Participants, however, varied in their belief in TCM and their understanding and acceptance of the Chinese concepts of food use. Thus the use of TCM and self-medication practices differed among participants, as does the use of alternative health practices in "mainstream" Canadian society.

The Chinese Cancer Patients: Special Issues

Participants in this study came from Hong Kong, China and Taiwan, and were of diverse socio-economic and political backgrounds. They varied in terms of educational levels and English language skills. When encountering the Canadian health care system, their experiences are likely to have been coloured by what occurred prior to immigration. For some, the despair over family separation added to their devastation when diagnosed with a potentially terminal illness such as cancer. Some of them experienced language barriers which affected their understanding of their disease and impeded their willingness and ability to be involved in treatment decision-making. Finally, as previously discussed, there were questions raised relating to the efficacy, accessibility and cost of high quality TCM practitioners in Canada. While not all participants wished to access TCM, others were inhibited from doing so by the lack of a regulated pluralistic health care system in Canada.

Possible Meanings in the Findings

Treatment decision-making preferences among cancer patients has been studied extensively. Even though patients' involvement in treatment decision-making has been advocated (Bartholome,1992; Emanuel & Emanuel, 1992), how it is achieved is less clear and the process by which it is accomplished is complex. What is clear is that patients want to be informed of their diagnosis, treatments and prognosis. Whether they use that information to make their own decisions varies and a multitude of factors influence their willingness to participate. Patients' personal characteristics, their relationship with and expectation of their physicians, and their perceived ability to be involved are influencing factors. Furthermore, the stage of their illness, the meaning they attribute to their illness, and whether their involvement in decision-making are encouraged affect the process of treatment decision-making.

In any treatment decision-making scenario, there are at least the physician and the patient involved. The physician, by virtue of position, has information that the patient wants. The patient, on the other hand, has personal information that the physician needs in order to make a decision suitable for that particular patient. Pierce (1996) said that patients assess options in the context of their lives and choose the one that is most salient to them. Kelly-Powell (1997) described the concept of a personalized choice. She said that patients make decisions based on their perceptions of past events, present life circumstances, and future plans. Patients could contribute to the decision-making process by revealing what is important to them. Therefore, the best treatment decision-making outcome is one in which information is shared and options discussed. Mutual understanding may be achieved through communication between the physician and the patient.

Bartholome (1992) advocates a shared decision-making model, one that involves dialogue between the patients and the physicians. Pierce (1997) describes the process by which sound decision-making is achieved. She said that the decision-making process consists of many steps and that health care professionals have a responsibility to ensure that all steps are in place. Steps include an assessment of the understanding of the decision-maker (patient) towards the problem (disease), assessment of needs for additional information, and determination of patients' individual values, beliefs and personal circumstances that may influence their choice. Therefore, optimal decision-making for cancer treatment involves communication between physicians and patients. This is similar to Degner and Sloan's (1992) collaborative scenario (Appendix G) which supports the notion that patients want some kind of involvement in the treatment decision-making.

Do all patients want to be involved in treatment decisions? Previous research has found considerable variation among cancer patients' beliefs about personal control. Perhaps there are times when patients want to delegate this responsibility to their physician. Emanuel and Emanuel (1992) said there are four models of physician and patient relationship that illustrate four levels of patient involvement in treatment decision-making. These four models are paternalistic, informative, interpretive and deliberate. They said that all four models are appropriate depending on the circumstances. It is possible that upon learning the cancer diagnosis, the emotional impact is so great that many patients want to delegate the treatment responsibility to their physician in an effort to protect their psychic integrity and to maintain normalcy in their lives (Kelly-Powell, 1997). There are some patients who will relinquish their control to their physicians and the basis for that action is trust.

Patients, by nature of their position, are vulnerable. Having to place total trust in their physicians in life-threatening circumstances makes them even more vulnerable. Trust can be inspired by the physicians' expertise, and their caring mannerism towards patients. Participants expressed that they had come to trust their physicians for these reasons. Trust can also be based on a sense of helplessness. A patient may simply feel inadequate to understand what is happening and, therefore, leaves everything to the physician. Such was true of one participant. Trust can also be misplaced. One participant felt he mistrusted his physician and that he was misled with his cancer diagnosis and treatment.

Trust in their physician may inspire patients' hope and facilitate coping with illness (Ridder, Depla, Severens & Malsch, 1997). It is important for health care professionals to foster this trusting relationship. One of the ways to inspire trust is to communicate with patients, to reach out and try to understand them individually. Communication inspires and fosters trust between patients and their caregivers. Communication affects information dissemination and prepares patients to make treatment decisions. Communication allows for information exchange between physicians and patients which affects the decision-making outcome. Inadequate English language skill was a major barrier to communication among some of the participants, and rendered full participation in decision-making impossible. These Chinese patients required additional assistance to ensure that information was shared with them. There are ways to improve communication between health care providers and non-English speaking patients. Use of interpreters, translated written information, and videotapes are effective ways to disseminate information and facilitate communication. Using family members for interpretation was problematic as some participants questioned the accuracy of the information exchanged and the possibility of family members screening the information given to the patient.

From the data, we learn that the Chinese people in Edmonton are diverse. They do not share the same difficulties and issues. In caring for this diverse population group, what are the challenges for health care professionals? How should care be provided so as to fit the mandate for culturally sensitive care? What do health care professionals need to know and to do? In the paragraphs to follow, the significance of the findings for health care professionals is discussed.

Significance for Health Care Professionals

The guiding question to this thesis is "Do Chinese cancer patients have special needs?" The summary of the findings reveals that some of them have special needs and some do not. What can be the possible explanation for these findings? What is the significance of these findings for health care professionals? In the paragraphs to follow, I will discuss what we know about Chinese immigrants and how that knowledge might affects our clinical work with them.

There is a lack of research literature about Chinese immigrants to Canada. Much emphasis is placed on immigration experiences and transition difficulties post-migration. What we lack is understanding of how their experiences prior to immigration differ and how these experiences may affect their current expectations of the health care system. Chinese immigrants to Canada are a diverse population. It is erroneous to think of them as homogenous. When research has been done on this group, too much emphasis has been placed on looking at the similarities among Chinese immigrants and not at their differences.

Existing literature typically describes the Chinese peoples' values, beliefs and health practices as very traditional. The problem is that such information does not truly represent the Chinese people we see in Canada. Since Chinese immigrants come from countries like China, Hong Kong and Taiwan, which have different political, educational and health care systems, these people are different in their understanding of traditional Chinese ways. When we draw on existing literature that describes the Chinese people, and when this existing literature typically draws on out-of-date information about the Chinese, the discrepancies between what we think we know and what is true can be great. The truth is that we know very little about Chinese immigrants in Canada. We do not know much about their belief in TCM. We do not know the extent of their belief in and the influence of Confucian teaching. The existing literature is not reflective of what this population is really like.

There is another reason for our misunderstanding about the Chinese population and that is their variability in socio-economic background and education levels. Hesseler (1978) and Li (1982) described the diversity within the Chinese population and Li (1988) specifically described the impact of socio-economic status in influencing peoples' difficulties after migration. Gupta (1978) said that there are more similarities between a rich person in London and Bombay than there are similarities between a rich and a poor person in the same geographic location. The role of socio-economic status in affecting people's lives and in affecting their illness experiences is undeniable.

It is important for health care professionals to assess Chinese patients individually and to recognize their individual special needs. The existing literature only offers general information about the Chinese population and one has to be cognizant that it may not be accurate at the level of the individual. The Chinese population, amongst themselves, are dissimilar. Literature cues us to the range of possibilities but offers little information about specific patients.

How do we learn about the Chinese population? One of the things we can do is to increase research. By studying this population, we come to know more about issues we are confronting. Another way is to disregard our previous assumptions and just ask the questions. Listening to their voices allows for better understanding. As one nurse, asked after a year of participating in action research project relating to cross-cultural health care, stated: " I now make fewer assumptions and ask more questions" (Ogilvie, Chiu, Wrightson, Fung, Ilesic, & McPherson, 1997, p. 11).

Reflections Pertaining to Nursing

Leininger (1967) recognized the diversity of the people nurses serve. By that, she meant that our patients come from diverse backgrounds. She recognized the challenge of gaining knowledge about values, beliefs and practices and then using this knowledge in the nursing care of all people, both those who are well and those who are sick. She recognized that there was an increased mix of people from different ethnic backgrounds and that cultural knowledge and understanding was integral to high quality care. The specialty of transcultural nursing was formed and knowledge of specific cultural groups gathered.

Now, in the 1990's, we recognize another kind of diversity; the within group diversity that is just as prominent as the between group differences (Hessler, Nolan, Ogbru & New, 1978; Li, 1988). The recognition of within group diversity has great importance in delivering culturally sensitive care. When we draw on literature that describes the Chinese population, we need to ask ourselves the questions, "Does this information accurately describe my patient? How can I find out more?" A better way to assess that person is to reach out, and ask them the questions. It is important to bracket what we read and to assess patients individually.

Implications for Nursing Research

I believe that this study and its findings support the importance of research and research-based practice. The findings offer some basic understanding of what this population may experience in dealing with their cancer. LeCompte and Goetz (1982) state that ethnographic research is different than positivistic research and therefore its contribution to scientific progress is different. They stated that ethnography offers depth and data gathering that "necessarily precedes hypothesis formulation and revision or may focus on descriptive investigation and analysis" (p.32).

The study findings challenge our assumptions about Chinese immigrants and provide information on the Chinese cancer patients' illness experiences. The findings from this study may provide baseline information with which to build more research on this population group. Questions that come to mind include: What are nurses' perceptions about Chinese patients? What effects do different information strategies have on Chinese patients' understanding and on their willingness to participate in decision-making?

Having seven out of ten participants with breast cancer lent more in-depth information about the issues faced by Chinese women having breast cancer. This is also a limitation as breast cancer is quite curable when discovered early as was the case with these women. Further studies should include Chinese patients with other tumours who require more extensive treatment protocols. Further study on Chinese people's utilization and understanding of TCM would yield interesting findings.

In doing this study, I have come to know several Chinese cancer patients and have listened to their stories. Reflecting on these stories, I realize how strong these people are. The Chinese cancer patients' stories are seldom told or heard. When given a chance, Chinese cancer patients are able and willing to articulate their views. It is a challenge for health care professionals to reach out across cultural and linguistic barriers and say to their patients, " Tell me about you. How may I help you?"

Personal Reflections

Doing this thesis has meant more than a quest for knowledge. It has meant a personal discovery. I have, in doing all this work, and in talking to these Chinese people, come to increased knowledge about myself. Being a Chinese person who has become Canadian and realizing what this means, I can now move forward, with increased clarity, in what my role is and what I should do in the future.

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Appendix A

Letter to the Physicians

Dear______________________

I am a registered nurse and am in the Master of Nursing degree program at the University of Alberta. I am currently conducting a research study about the experience of Chinese cancer patients and am interested in what information they perceive as important and how much they would like to be involved in treatment decisions. I would appreciate your help in identification of possible participants. Study participants must have the following characteristics:

1.First time diagnosed cancer patients with or without surgical interventions and who are referred for further treatment options.
2.Any type of cancer.
3.Within six months of initial diagnosis
4.Cantonese as the first language
5.Born outside of Canada

Please give the information sheets to clients that match these characteristics and obtain verbal permission for me to contact them. Once I have the name and phone number, I will phone them to further discuss the study and invite them to participate. If you have any questions or concerns, please call me at 4769766 and I will be pleased to answer them. I look forward to hearing from you. Thank you for your assistance.

Sincerely,

Agnes Cheng, R.N., BScN, M.N. Candidate

Appendix B

Information sheet to the Prospective Participant (English Version)

Hello. My name is Agnes Cheng. I am a registered nurse and am a student in the Master of Nursing degree program at the University of Alberta. I am interested in finding out how Chinese cancer patients make treatment decisions and what information they perceive as important. Your taking part in the study will allow me to have greater understanding of the Chinese experience which is important for nurses and doctors in order to give better care.

You will be interviewed twice. The first interview will be about an hour long, and will take place wherever you are most comfortable. All interviews will be conducted in Cantonese and will be tape recorded. You may refuse to answer any questions or terminate the interview at any time. Your name will not be used in any reports of this study; a code name will be used in place of your name.

If you are interested in participating, please let the person who gave you this information sheet know. I will telephone you in a few days to set up a time for our meeting. You may also phone me at 4769766 at any time to ask me questions about this study. Your participation in this study is completely voluntary.

Thank you for considering being involved in this study. I look forward to talking with you.

Sincerely,

Agnes Cheng R.N. BScN, M.N. Candidate

Appendix B

Information Sheet to the Prospective Participants (Chinese Version)

研究的通知

喂，我的名字是鄭黃振嫻，我是一個註冊護士，現在亞省大學完成碩士學位。我有興趣去研究中國癌症病人對治療選擇的決定，同時去了解他們對病情資料的需要，你的參與可以幫助我去了解中國癌症病人的經驗。這種知識會幫助醫生及護士去料理中國病人，你會接受兩次訪問，第一次訪問大約一小時，訪問會在你方便的地方進行，所有訪問用廣東話及錄音，你有權利隨時終止訪問或退出研究，你的名字會受保障，用假名代替。

如果你有興趣參加，請告知向你接觸的人員，我會在幾日內，與你通電話，約一個見面的時間，你可以來電話 4769766 問我問題，你的參與是完全自願的。

謝謝你表現興趣參與這研究，希望有機會與你傾談。

Appendix C

Advertisement of Research Study (English Version)

I am a nurse in the Master degree program at the University of Alberta. I am studying how Chinese cancer patients choose treatment options. I am looking for people who are first time diagnosed with cancer and are within six months of cancer diagnosis. You must be born outside of Canada and your first language must be Cantonese. I want to find out what information you feel is important and how you prefer to be involved in the treatment decisions.

Your taking part in this study will help me understand Chinese cancer patients. This knowledge may help health care workers to provide better care. Involvement in this study will not harm you but may benefit others.

If you are interested, please call Agnes Cheng at 476-9766 or call the Chinese community service center at 429-3111 and I will contact you with more details.

Appendix C

Advertisement of Research Study (Chinese Version)

研究的邀請

我是亞省註冊護士，目前正在進行護士的研究，去了解中國癌症病人對治療方法決定的經驗。如果你在最近六個月內受診斷，首次診斷爲癌症，你不是在加拿大出生，你的母語是廣東話，便可以參與這個研究，我希望能了解你對癌症資料的需要，以及參與治療方法的決定。

你，參加這研究，會幫助我明白中國癌症病人的需要，也可以增加醫藥護理人員對中國癌症病人的認識，並能有效地照料中國癌症病人，參與這研究不會導致損害。

你如果有興趣參加，請致電我本人(鄭黃振嫻 4769766)，或致電華人社區服務中心（4293111），我便會與你聯絡。

Appendix D

Consent Form (English Version)

PROJECT TITLE: THE EXPERIENCE OF CHINESE CANCER PATIENTS IN TREATMENT DECISION MAKING

This consent form is designed to give you an idea of what this research study is about. It explains what will happen to you if you choose to be in the study.

If you have any questions regarding this study, please be sure to contact me (the investigator), my supervisor, or your doctor. Read this form carefully to make sure you understand. You will get a copy of this form to keep.

I, Agnes Cheng, will discuss this study with you. I understand that your doctor has talked to you about this study. You have given me permission to phone you. Your taking part in this study is voluntary. You are will not be affected whether you take part or not.

This study may teach me something that will help others in the future.

BACKGROUND INFORMATION

There are few studies of cancer patients'information needs and treatment decision-making preferences. Due to language barriers, little is known about Chinese patients. We need to understand this population, so health professionals can provide better care.

STUDY PURPOSE

The purpose is to study Chinese cancer patients, to find out how they make cancer treatment decision and also to find out what information they perceive as important in making decisions. Since this has not been studied before, any findings will give us valuable insights about this population.

STUDY DESIGN

If you choose to take part in this study, you will be interviewed twice in Cantonese. The interviews will be audiotaped and information will be translated into English for analysis.

POTENTIAL BENEFIT

Participation in this study may be of no personal benefit to you. However, based on the results of this study, it is hoped that, in the long-term, patient care can be improved.

POTENTIAL HARM

Participation will not cause you any harm. If our discussion evokes strong emotional reaction and you desire to have some counselling assistance you may be referred to a psychologist of your choice.

WITHDRAWAL FROM STUDY

You may withdraw from the study at any time with no ill consequences.

CONFIDENTIALITY

The information that we collect as part of this study will be shared with other researchers. The findings may be published. However, you name will not be identified in any of these reports.

I will keep all the material I collect for this study in a locked cabinet and only my research committee and I will have the key to this cabinet.

In the future, other researchers may want to use this material for new studies. Although we will not contact you when this happens, each new study will be reviewed to make sure that it is ethical.

UNDERSTANDING OF PARTICIPANTS

I am signing this form to show that I have read the consent form, and that I agree to take part in the study as a subject.

I can refuse to take part or may withdraw from this study at any time without jeopardizing my health care. I am free to ask for further explanations about this study. I understand that Dr Ogilvie at (403) 492-9109, Agnes Cheng at (403) 476-9766, Lucy Tse at the Chinese Community Service Center (403)429-3111, or Dr_____________at(403)__________will answer my questions I have about this study.

I will get to keep a copy of this consent for information and for future reference.

(PRINT NAME CLEARLY)

NAME OF PATIENT______________________________

SIGNATURE OF PATIENT__________________________

NAME OF INVESTIGATOR__________________________

SIGNATURE OF INVESTIGATOR_____________________

DATE______________

Appendix D

Consent Form (Chinese Version)

研究自願書

研究題目：華裔癌症病人選擇治療的經驗

AGNES CHENG
鄭黃振嫻
FACULTY OF NURSING
UNIVERSITY OF ALBERTA
(403) 476-9766

Dr. LINDA OGILVIE
THESIS SUPERVISOR
FACULTY OF NURSING
(403) 492-9109

這自願書是向你介紹這個研究，同時告知你參與這研究的程序。請留心閱讀，了解這自願書的內容，你可以保留一份副本作參考，無論你決定參加與否，你的醫療是不會受影響。這研究未必對你個人有利益，但我希望這研究的結果可以對其他人有所幫助。

背景：
過去有很多研究去了解病人對癌病治療的選擇及對癌病資訊的需求，但對華裔的了解不多，我們需要對華裔癌症病人多了解，使醫務人員能更有效地幫助他們。

研究的目的：
目的是訪問華裔癌症病人喜歡怎樣選擇治療的方法，同時需要什麼資訊去做決定。由於這題目在過去未有研究過，研究的結果會增加我們對華裔癌症病人的認識。

研究的設計：
如果你有興趣參與，你會被訪問兩次，每次訪問內容會以錄音機記載，同時錄音資料會被翻譯成爲英文，以作分析用途，每次訪問大約一小時。

參與的利益：
參與這研究不會直接給你益處，但這研究的結果或會改善以後華裔病人的料理。

參與的害處：
參與這研究不會對你有害處，若果訪問過程令你情緒不安，我們可以安排心理輔導家給你幫助。

退出研究:
你可以隨時退出研究，不會有不良的後果。

個人保密:
這研究所收集的資料，會與其他研究員討論，研究的結果會作論文發表，但你的名字會保密，不會在這些報告中出現，所有的資料會藏在上鎖的櫃內，唯有研究員及老師可以參閱這些資料。
以後，其他研究員或會用這些資料，我們不會再打擾你，但每個新的研究也經研究標準委員去審視及批准。

參與的了解:
我讀完這自願書，決定參與這研究。
我可以隨時退出，我的醫療不會受影響，我可以隨時向以下有關人仕發問問題，

DR. OGILVIE (403) 492-9109 或
AGNES CHENG (鄭黃振嫺)(403) 476-9766 或
LUCY TSE (謝太) 於華人社區服務中心(403) 429-3111

或 ______________________ 醫生(403)______________________。

他們都可以回答我的問題，我會保留一份自願書作參考。

______________________ ______________________
參與者姓名 參與者簽名

______________________ ______________________
研究員姓名 研究員簽名

____
日期

Appendix E

Information Collection Sheet

1. Age
2. Sex
3. Occupation
4. Country of origin
5. Length of time in Canada
6. Education
7. Family Composition
8. Language(s) Spoken____________________
   Read ____________________
   Written____________________
9. Cancer History:
10. Site of Cancer
11. Length of Cancer
12. Treatment Undergone(surgery or no surgery)
13. Current treatment options

Appendix F

Interview Guide:

Several semi-structured questions will be asked during the first interview.

What is your understanding of your cancer diagnosis and treatment?

What information have you received?

Do you understand this information?

What information do you feel you still need in relation to your cancer diagnosis, treatment and prognosis?

How would you like this information given?

What decision have you reached in terms of your cancer treatment?

How was this decision made?

What role do you prefer in terms of making treatment decisions about your cancer?

What role do you prefer your family to play?

Are there any other things that are important to you in terms of understanding your cancer and making treatment decisions?

Is there anything else you would like to share with me?

Appendix G

Card Sort (English Version)

A. I prefer to make the final selection about which treatment I will receive.

B. I prefer to make the final selection of my treatment after seriously considering my doctor's opinion.

C. I prefer that my doctor and I share responsibility for deciding which treatment is best for me.

D. I prefer that my doctor makes the final decision about which treatment will be used, but seriously considers my opinion.

E. I prefer to leave all decisions regarding my treatment to my doctor.

Degner,L.F., & Beaton, J.I. (1987). Life-death decisions in health care. New York: Hemisphere Publishing Corporation.

Degner, L.F., & Russell, C.A. (1988). Preferences for treatment control among adults with cancer. Research in nursing and health, 11, 367-374.

Degner, L.F., & Sloan, J.A. (1992). Decision making during serious illness: What role do patients want to play? Journal of Clinical Epidemiology, 45(9), 941-950.

Appendix G

Card Sort (Chinese Version)

A. 我自己喜歡作最後選擇治療的方法。

B. 我喜歡自己作決定，但首先慎重地考慮我的醫生的意見。

C. 我喜歡與我的醫生一同負責選擇最適合我的治療方法。

D. 我喜歡我的醫生選擇治療的方法，但首先考慮我的意見。

E. 我喜歡完全由醫生決定治療的方法。

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St. Boniface General Hospital Research Centre
Hôpital General St. Boniface Centre de Recherche

FAX TRANSMITTAL

DATE: June 27/96

TIME: 14:10 hrs
OF PAGES: 1

SEND TO:
Name: Agnes Cheng
Organization: Edmonton
Fax Number: (403) 450-7685

FROM: L. Degner
St. Boniface Hospital Research Centre

Telephone: (204) 235-3480
Fax Number: (204) 231-1918

MESSAGE: I am delighted to have you use the cards! I would like to receive a copy of your results, if I may.

Original to follow in mail: ____ yes ____ no

University of Alberta
Edmonton
Canada T6G 2G3

Faculty of Nursing
3rd Floor Clinical Sciences Building

Certification of Ethical Acceptability for Research Involving Human Subjects

---

NAME OF APPLICANT(S): Agnes Cheng, MN Candidate

TITLE OF PROJECT: "The Experience of Chinese Cancer Patients in Treatment Decision Making"

The members of the review committee, having examined the application for the above named project, consider the procedures, as outlined by the applicants, to be acceptable on ethical grounds for research involving human subjects.

18 Dec 96.
Date

Beverley O'Brien
Beverley O'Brien, PhD
Chair, Ethics Review Committee

ERC 96-107
5005-02-107

Date: Tue, 26 Jan 1999 14:58:50 -0400
From: "Rachel E. Spector" <spector@bc.edu>
Reply-To: spector@monet.bc.edu
To: A Cheng <agcheng@gpu.srv.ualberta.ca>
Subject: Re: permission

Hello - It is a great honor that you see these words of mine as something that can be a part of your thesis. Of course, you have my permission. Thank you for including me in your thesis. I wish you the very best of good luck and good health.
Sincerely,
Rachel E. Spector
On Mon, 25 Jan 1999 15:35:00 -0700 (MST) A Cheng
<agcheng@gpu.srv.ualberta.ca> wrote:

> Dear Dr Spector: Recently I read your book "cultural diversity in health and illness" and I found your poem that I would like to be part of my thesis. Do I have your permission to use it? This poem reads" To understand the cultural needs, sameness and differences of people......mutual understanding". If you agree to let me use it, please e-mail your permission to University of Alberta, Edmonton, Alberta, Canada. My e-mail address is agcheng@gpu.srv.ualberta.ca. Thank you.
>

Rachel E. Spector
spector@mail1.bc.edu
Boston College